UNIVERSITY OF ALBERTA

SEXUALITY FOR BREAST CANCER SURVIVORS: RECONSTRUCTING SEXUAL SELF-IMAGES

BY

LIANA JILL TURNER ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of DOCTOR OF PHILOSOPHY

IN

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled SEXUALITY FOR BREAST CANCER SURVIVORS: RECONSTRUCTING SEXUAL SELF-IMAGES submitted by LIANA JILL TURNER in partial fulfillment of the requirements for the degree of DOCTOR OF PHILOSOPHY in COUNSELLING PSYCHOLOGY.

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DEDICATION

Dedicated in loving memory of Lulu Pearl Boates Turner

A woman of integrity, wisdom, beauty, and strength, who,
in her quiet, and often humorous ways, taught me the ways of being a woman.

ABSTRACT

The purpose of this current research is to describe the experience of sexuality for breast cancer survivors. When previously researched, quantitative methods have prevailed and have addressed such topics as frequency of intercourse, ratings of painful intercourse, and sexual desire. In addition, questionnaires that have been used to study women's sexuality often lack the sensitivity required to study such a construct. Although performance-based aspects of sexuality are important elements, they are limiting and do not adequately address survivors' concerns. Until now, breast cancer survivors have not been active participants in the construction of their own sexual paradigms. Specifically, this research recognizes the importance of understanding women's descriptions of sexuality. Eight participants were interviewed utilizing an open ended format and the data were analyzed in accordance with qualitative descriptive methodology. Qualitative descriptive methodology was employed as it emphasizes meaning and understanding of an individual's experience. This research resulted in participants' rich descriptions of a reconstructed sexual self-image after breast cancer. They described their constructions of sexuality before they were diagnosed with breast cancer and how these constructions were challenged by breast cancer and its treatment. The women created meaning out of the changes in their bodies and sense of selves as women, and integrated this with their previous understandings of their sexuality. These new meanings were then integrated into new sexual self-images. Compared to the current literature, the participants provided inclusive and expansive views of sexuality as their sexual meanings transcended performance-based aspects of sexuality including descriptions of deepened relationships and increased intimacy.

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CHAPTER ONE
INTRODUCTION

In 1998, breast cancer was the most frequently diagnosed cancer in women (National Cancer Institute of Canada, 1998),with an estimated 19,300 newly diagnosed women with breast cancer, and 5,300 breast cancer related deaths. Furthermore, estimates for 1998 show that 10,800 (56%) of new breast cancer cases occur in Canadian women aged 60 or more and 2,650 (50%) of breast cancer deaths occur in women aged 70 or more (National Cancer Institute of Canada, 1998). According to the National Cancer Institute of Canada (1998), the diagnosis of breast cancer rose steadily over the past decade, whereas mortality rates for breast cancer declined slightly since 1985 and particularly since 1990.

Cancers, such as breast cancers, that directly involve body parts that are related to sexual functioning can impact a woman's sense of herself and her sexuality (Dobkin & Bradley, 1991). When examining the literature on breast cancer and sexuality, previous researchers have explored narrow aspects of sexuality, such as intercourse and other performance-based aspects of sexual functioning, through predominantly quantitative methods (Andersen, Anderson, & deProsse, 1989; Wilmoth & Townsend, 1995). This present research examines sexuality from a woman's perspective after she has experienced breast cancer. Before this research is presented in further detail, the incidence, risk factors, psychological difficulties, and sexuality relating to breast cancer will be briefly explored.

Increased Incidence and Risk Factors

The increase in breast cancer diagnoses is being attributed to the increased use of mammography to detect breast cancer since the 1980's. As more and more women are being screened with mammography for breast cancer while they are healthy, more breast cancers can be diagnosed at a much earlier stage, resulting in earlier treatment

and a better chance at lengthened survival (National Cancer Institute of Canada, 1998). This rise in breast cancer incidence is also being attributed to women's hormonal and reproductive histories. Today, more women are delaying childbirth and having children later in their lives, and as a result, this delay may be contributing to hormonal risk factors for developing breast cancer (National Cancer Institute of Canada, 1998; Olivotto, Gelmon, & Kuusk, 1995). It appears that the younger a woman is at her first period, and the older she is when she goes into menopause, the more likely she is to be diagnosed with breast cancer. That is, the more menses a woman has over her lifetime, the more prone she is to develop breast cancer. In addition, pregnancy also seems to affect breast cancer. Women who have never been pregnant seem to be more at risk than women who have been pregnant before the age of 30. Also, women who have their first pregnancy after age 30 have a greater risk of developing breast cancer than women who have never been pregnant at all (Love, 1995). For most women, the diagnosis of breast cancer creates an environment of stress, anxiety, fear, and other psychological difficulties.

Breast Cancer and Psychological Difficulties

Surgery, chemotherapy, and radiation can have an adverse effect on the general psychological functioning (Fallowfield, 1996) of women with breast cancer. Although cancer is a physical disease, it has many psychological ramifications; such as depression, anger, grief, loss, fear, anxiety, concerns with body image, and concerns with sexuality. Anxiety and depression are the two most prevailing emotional difficulties experienced by women with breast cancer (Bulman, 1992; Millar, Jelicic, Bonke, & Ashbury, 1995). These emotional difficulties may present major complications to satisfactory adjustment during diagnostic, treatment, and recovery periods, and may delay return to previous life patterns. Researchers have described a wide range of disruptions in day to day living due to breast cancer diagnosis and treatment, such as, changes to work and changes to family life. In

addition, younger women who have been diagnosed with breast cancer seem to experience more psychological distress than older women. Younger women may be faced with potential infertility caused by cancer treatments, and women who are not in a committed relationship may fear rejection from a potential mate (Schover, 1994). However, it has also been documented that many of these treatment-related physical and psychosocial problems resolve during the first year of follow-up evaluation (Ganz, Schag, Lee, Polinsky, & Tan, 1992; Wolberg, Romsaas, Tanner, & Malec, 1989). These psychological difficulties can indirectly impact a woman's sense of sexuality as described in the following section.

Breast Cancer and Sexuality

Cancer of the breast can be particularly difficult for some women as breasts are symbolic of sexuality and femininity in many Western cultures (Fallowfield, 1996; Ghizzani, Pirtoli, Bellezza, & Velicogna, 1995; Smith & Reilly, 1994). Since breast cancer involves body parts that are directly related to sexual functioning and sexuality, it may have a significant effect on a woman's view of herself as a woman. Previous research has reported that many women treated for breast cancer experience changes in their sexual lives (Andersen, 1984; Andersen et al., 1989; Dobkin & Bradley, 1991). For instance, based on the results from several studies, researchers have estimated that one-third to one-fourth of women experience sexual difficulties after treatment. Some of these difficulties include less frequent intercourse, lowered sexual excitement, and difficulty reaching orgasm (Andersen, 1984; Northouse, 1994).

Breast cancer treatment itself, such as surgery, chemotherapy, and radiation, can have a direct impact on sexuality. Surgical alterations to a woman's body can have a tremendous impact on how she views her body and her sexual self. When body image is threatened by mastectomy or lumpectomy, women have made comments such as "feeling a freak", "feeling half a woman", and "feeling mutilated"

(Maguire, Brooke, Tait, Thomas, & Sellwood, 1983). In addition to surgery, chemotherapy can be much more damaging to a woman's sexuality and body image than the surgery itself (Schover et al., 1995). Chemotherapy is primarily used to destroy cancerous cells; however, by doing so, many of the chemotherapeutic agents destroy ovarian functioning along with the tumor. When this ovarian failure occurs, estrogen hormones and testosterone hormones, which are necessary for normal female sexual functioning, are no longer released and sexual difficulties may ensue. These difficulties include painful intercourse and a loss of sexual desire (Kaplan, 1994).

Schover (1988a) reported that women can also experience a lack of desire due to the side-effects of chemotherapy. These side-effects include hair loss, nausea, weight loss or gain, fatigue, depression, hot flashes, yeast infections, and vaginal dryness. Certainly, these side-effects can also hamper sexual desire. Although these results provide important information on the impact of breast cancer on sexual functioning aspects of sexuality, they do, however, also provide a narrow perspective on women's sexuality. This present research strives to provide a broader definition of sexuality for breast cancer survivors.

Importance of Present Research

Although there has been a great deal of research on sexuality and breast cancer, researchers have focused on a narrow view of sexuality. Previous research has examined sexuality from a traditional intercourse based definition. Much of the research in this area has focused on intercourse and other performance-related aspects of sexuality in response to breast cancer treatment (Andersen et al., 1989; Andersen & Jochimsen, 1985; Ganz et al., 1996; Margolis et al., 1990; Schover et al., 1995; Wilmoth & Townsend, 1995). Intercourse between men and women, the frequency of and desire for intercourse, and satisfaction with sex are minor aspects of sexuality and this interpretation of sexuality neglects additional significant aspects that women

may find important. Such a view may lead researchers to neglect asking women with breast cancer what aspects of sexuality they find affected. As a result, it is important to examine sexuality from a women centered perspective of sexuality and breast cancer. Women centered sexuality is defined on the basis of what women have experienced about themselves in their own lives through feelings, experiences, and relationships (Bernhard, 1995). Kitzinger (1985) asserts that women's sexuality depends on what is happening around women, their feelings about their identity, and how they value themselves. In other words, the context of women's lives may impact their sexuality. Women's sexuality as defined by women is a diverse, full-bodied experience, not restricted to the act of coitus. As a result, the intent of this research is to explore the meaning of sexuality to breast cancer survivors.

Purpose of Present Research

The purpose of this study is to examine the impact of breast cancer on women's sexuality by allowing the women themselves to describe and identify the impacts of breast cancer. Such an approach has the potential of achieving a fuller understanding of this occurrence. As most of the literature on breast cancer and sexuality involves narrow definitions of sexuality, it is important that this research expands current literature by asking women themselves to define their own sexuality and how breast cancer may have impacted their sense of selves as women. Eight breast cancer survivors were interviewed about their experiences in an open-ended interview format that was initiated by the question "How do women experience and describe sexuality after breast cancer?". This research attempted to understand a woman's experience from her own point of view and she was encouraged to tell her story in any way she chose. Also, important early messages that the participants received about sexuality were also explored so that their examination of sexuality after breast cancer could be understood in light of their own personal experiences before their cancer diagnosis.

Methodology

To study the meaning of sexuality for women with breast cancer, a qualitative descriptive methodology was used in this research project. This method was chosen as it emphasizes meaning and understanding of a person's experience in a way that cannot be captured with questionnaires. Previous researchers in this area of study have used questionnaires that attempted to examine sexuality from more narrow, traditional based models which focused on sexual intercourse and sexual desire. These questionnaires do not elicit from the women themselves how they make sense of their sexuality. As a result, this research asked women to describe their sexuality and how breast cancer may have impacted their sense of selves as women and their sexuality. In this current research, a qualitative descriptive methodology was used to acquire personal descriptions of how breast cancer has impacted these women, and as a result, may provide a deeper, more complex, understanding of how women's sexuality may be impacted by breast cancer.

Outline of Dissertation

As this research study explores the meaning of sexuality to breast cancer survivors, Chapter Two includes a description of the current literature in the areas of breast cancer and sexuality. Research topics covered include the nature of breast cancer and cancer treatment, female sexuality, psychological and psychosocial responses to breast cancer, and breast cancer and women's sexuality.

An explanation of the qualitative methodology used to study the experience of sexuality for breast cancer survivors is presented in Chapter Three. Specifically, methodological issues, participant selection, and procedures and data analysis are explored. Chapter Four provides a thematic analysis of the interviews conducted with the participants. The themes are described and illustrated with quotations from the participants' interviews.

Finally, the discussion in Chapter Five offers an analysis of the women's

descriptions of sexuality and how these descriptions propose an expanded, reconstructed view of sexuality that differs from the current literature on breast cancer and sexuality. This reconstructed view of sexuality is explored through the common themes that the women shared during the interviews. This expanded view of sexuality is compared with the current literature on breast cancer and sexuality. Also, some of the participants shared some unique aspects of their sexuality. These aspects often went beyond any scholarly, research oriented definitions of sexuality and will be explored in this chapter. Finally, implications and limitations of this current research and directions for future research are described.

CHAPTER TWO
LITERATURE REVIEW

This chapter contains an overview of the literature pertaining to breast cancer and sexuality. More specifically, this chapter acquaints the reader with existing relevant research studies and establishes a need for the present research. Topics to be covered include the nature and treatment of breast cancer, myths and models of female sexuality, psychological and psychosocial responses to breast cancer, and breast cancer and women's sexuality. As this study dealt with a sample of women who experienced cancer, a brief overview of the literature and statistics on cancer, and more specifically on breast cancer, will be provided.

Cancer, Breast Cancer, and Breast Cancer Treatment

Cancer

Cancer is a group of more than 200 diseases. These diseases occur when cells become abnormal and keep dividing and forming more cells without order and control. A cancer cell has an abnormal chromosome from genetic change or previous damage. This changed or altered gene starts sending the wrong message from the message it should give. As a result, the cell begins to grow very rapidly. It multiplies again and again and again until it forms a lump or mass of tissue that is called a tumor, or cancer. Cancer starts with one abnormal cell that doubles and becomes two abnormal cells that, in turn, doubles and becomes four abnormal cells and this process continues. Cancers which grow quickly may double over one to four weeks, where slow growing cancers may take from two to six months to double in size. It may take up to five years before the tumor duplicates twenty times. At this time, the tumor may contain a million cells but will only be the size of a pencil tip. It may take many months or years before the tumor's doubling process has created a tumor that is large

enough to be detected by touch, x-ray, or cause symptoms such as pain or bleeding (Dollinger, Rosenbaum, & Hasselback, 1995). Cells in malignant tumors can invade and damage other tissue and organs. Cancer growths can also break away from the tumor and travel through the bloodstream or the lymphatic system to form new tumors, or metastases, in other parts of the body (National Cancer Institute, 1993). As this research includes participants who have been diagnosed with cancer of the breast, the following section focuses more closely on defining breast cancer.

Breast Cancer

As noted earlier, breast cancer is the most common malignancy in women. During their lifetimes, one in nine women is expected to develop breast cancer (National Cancer Institute of Canada, 1998). Staging of cancer is necessary to define the cancer, determine any metastasis, determine prognosis, and propose the treatment. Stage 0 refers to a non-invasive breast cancer. Stage I applies to a small lump (less than or equal to two centimeters) which does not seem to have spread to lymph nodes or other parts of the body. Women with a Stage I cancer have approximately an 80% to 95% chance of five-year survival. Stage II cancers are larger (between two to five centimeters) and there is no evidence of any metastases. Fifty percent to 70% of women with Stage II cancer survive five years after diagnosis. Stage III cancers are larger (greater than five centimeters) with lymph node involvement without any evidence of distant spread of the cancer. Women with Stage III cancer have a 30% to 60% chance of five-year survival. Stage IV cancers are the same as Stage III, except that there is evidence of metastases in other parts of the body. Cancer is not considered curable at this stage and women have a 5% to 20% chance of five-year survival (Olivotto et al., 1995). In this present research, women with evidence of metastases were not sought to participate as it was felt that these women may be focused on issues of survival and that metastatic disease may be a complicating factor in the telling of their stories.

Breast Cancer Treatment

Women who have been diagnosed with breast cancer are often given a choice in surgical procedures. Ideally, a woman and her surgeon will decide as to the best course of treatment. Together, they will decide upon either a mastectomy in which the whole breast is removed, or a lumpectomy in which the tumor and a small margin of surrounding healthy tissue is removed. The choice is often made after examining factors such as personal preference, size of tumor and its location, patient's age and overall health, and risks and benefits, ascribed to each treatment protocol (Olivotto et al., 1995). In addition to surgery, women may also undergo chemotherapy treatment when there is a risk of residual cancer cells regrowing as metastases throughout the body. Chemotherapy consists of drugs that are taken orally or injected into the vein to treat cancer and prevent its recurrence. Some women may also be given radiation therapy to kill cancer cells in which high-energy rays are used to damage the cancer cells so that they eventually die (Olivotto et al., 1995).

In the past, a surgical procedure known as the Halsted radical mastectomy, which removes the muscle underlying the breast as well as the breast tissue was the typical treatment. However, less radical surgery has proven to be just as effective for women diagnosed with breast cancer in the clinical Stages I or II (Olivotto et al., 1995). The modified or simple mastectomy, which removes breast tissue, and the lumpectomy which involves the local removal of the tumor have replaced the radical mastectomy. Stage I and II breast cancer patients treated with lumpectomy plus radiotherapy have equivalent long term survival rates to those treated with simple mastectomy or mastectomy plus radiotherapy (Fisher et al., 1989; Harris et al., 1990; Henderson, 1995).

For the purpose of this research, participants will have Stage I to Stage III breast cancer. Women with Stage IV breast cancer were not included as this may be a unique group of women as evidence of metastases may bring survival issues to the

forefront of their experience. As a result, issues of sexuality may only be complicated by the metastatic breast cancer. In addition, to obtain participants with a wide range of experiences, it was important to have a cross section of women for this research. As a result, participants have had any combination of treatment. That is, some women had surgery, chemotherapy, and radiation therapy, whereas others may have had surgery alone, or a combination of surgery and radiation.

Models and Theories of Female Sexuality

When examining what sexuality means to breast cancer survivors, it is important to explore pre-existing models and theories of female sexuality. Sexuality is not easily defined as it comprises many different life experiences, attitudes, and behaviors with each person's definition of sexuality being unique and personal. Sexuality involves many components and interrelationships. Sexuality is learned through interacting with others at home, at school, and through the media, but meaning is also created individually. That is, women make sense of messages from others and internalize and integrate these messages and personal experiences into their sense of selves as women. Consequently, although people are influenced through their interactions with others, they are also influenced through their own experiences and desires which may differ from those around them (Daniluk, 1998; Nelson, 1997).

In many cases, the study of sexuality has been treated as synonymous with the history of male sexuality (Nelson, 1997). Women's sexuality has been viewed as a mysterious entity. It has been formulated as reactive and responsive to male sexuality; that is, that women's bodies are vehicles for men's sexual pleasure (Kitzinger, 1985). Many traditional views of sexuality purport that sexuality "is located in the body and involves genital contact" (Daniluk, 1998, p.4) which contributes to a "phallocentric, goal-oriented conceptualization of sexuality" (p.5).

However, in the past three decades, women have challenged this view of female sexuality and have provided many new and exciting ideas (Nelson, 1997). Sexuality scholars believe that men and women experience sexuality differently. Many men view sexuality mainly as genital activity, whereas most women view it as a total body experience that cannot be separated from the context of their lives (Bernhard, 1995; Kitzinger, 1985). Men may think of sexuality in terms of the number of times they have engaged in a particular activity, as in the "he shoots, he scores" model of male sexual activity (Daniluk, 1998, p.212). Whereas, for women, the focus may be on the meaning of sexual activity and the range of feelings experienced. Women's sexuality has been described as unique, that no two women may experience sexuality in a similar manner, and that women's sexuality is not static, but dynamic, changing throughout her lifetime (Bernhard, 1995; Daniluk, 1998). Women focus on the meaning of sexuality and view it as a total body experience; however, previous researchers in the area of breast cancer and sexuality have focused on intercourse related aspects of sexuality. Therefore, the purpose of this research is to ask breast cancer survivors directly what is important to their sense of sexuality and what sexuality means to them. If, indeed, women's sexuality is dynamic and changing throughout her lifetime, then perhaps, significant events such as the diagnoses of breast cancer can create further changes to women's sexuality. As a result, it is important to ask women who have been diagnosed with breast cancer if and how their views of who they are as women have been altered as a result of their experiences.

Models of Female Sexuality

The purpose of this section is to describe current theories and models of female sexuality, and related literature on the pioneering work of Masters and Johnson's Sexual Response Cycle.

Bernhard's model of female sexuality.

One model of female sexuality describes it as a "multidimensional, biopsychosocial phenomenon" which incorporates four components: sexual desire, sexual response, view of oneself as female, and presentation of oneself as woman (Bernhard, 1988). Sexual desire, or drive, refers to the inborn urge for sexual activity which is produced by brain activity and experienced as a specific sexual sensation that motivates a person to search for a sexual experience. This aspect of the model includes the woman's interest in sexual activity as well as her preference for a sexual partner, whether that be a partner of the same and/or opposite sex (Bernhard, 1988).

The second component of this model, sexual response, mostly refers to the biological aspects of sexuality. For example, it includes the physical ability to engage in sexual activity and experience orgasm. Bernhard (1988) continues to explain that all body systems are involved in sex and that any impairment to a system may result in sexual difficulties. The view of oneself as female is the third component of sexuality. This is a self-perception that may include women's gender identity (identifying as female); a sense of having personal characteristics which may be considered feminine, masculine, or both; and body image (i.e., a woman's view of her body and its relationship to the environment) (Bernhard, 1988).

Bernhard's final component of sexuality is the way a woman presents herself to the environment. Also known as "gender role behavior", this aspect includes all the behaviors that a woman uses to relate to and communicate to the world that she is a woman. This external presentation may represent a woman's internalization of social and cultural stereotypes and expectations of how a woman should behave in a particular culture (Heilbrun, 1981). Previous researchers in the area of breast cancer and sexuality have focused on only one aspect of Bernhard's multidimensional biopsychosocial model of female sexuality. That is, researchers have focused on the biologically based component of sexual response by designing questionnaires that

study sexual activity and orgasm. As a result, researchers have neglected the other three psychosocial components that Bernhard also describes as making up female sexuality. Consequently, this present research allows women to explore additional psychosocial dimensions of sexuality that are included in Bernhard's model, such as body image and the possible impact of social and cultural expectations.

Masters and Johnson's Sexual Response Cycle.

When examining the literature on sexuality and breast cancer, it is evident that a number of studies use the Masters and Johnson's sexual response cycle when formulating their research about biological sexual functioning (Andersen et al., 1989; Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998; Margolis et al., 1990; Wilmoth & Townsend, 1995). As a result, it is important to summarize their results and discuss the implications of their findings. In the 1960's, Masters and Johnson (1966) first identified the sexual response cycle by measuring sexual activities such as coitus and masturbation. This cycle was a highly ordered sequence of physiological responses to sexual stimuli. Masters and Johnson studied the sexual arousal and orgasm in men and women and created a description of sexual response which is divided into four phases. The researchers reported that the four stages of sexual response were virtually identical for both men and women. In the first stage, the excitement stage, both men and women experienced nipple erection. In the plateau stage, men and women experienced skin flushes, increased heart rate, generalized muscle tension, and hyperventilation. The orgasm stage is the third phase, and it is in this stage that specific muscles contracted, and hyperventilation and an increased heart rate continues. As a result of this research, women were distinguished from men in their ability to experience multiple orgasms. The resolution stage is the fourth and final stage. Here, both men and women experienced sweating, hyperventilation, and increased heart rates. Masters and Johnson's work also challenged some popular myths; such as the superiority of the vaginal over the clitoral orgasm. That is, the

clitoris was shown to be the site of sexual excitation and a distinctly separate vaginal orgasm was reported to be impossible.

Masters and Johnson's research was motivated by their beliefs in the equality of the sexes and, as a result, they were the first researchers to explore women's pleasure and satisfaction with sex. Certainly, they contributed greatly to the study of human sexuality. Nevertheless, for the purpose of this research, and unlike previous research studies in the area of breast cancer and sexuality, it is important to explore more than women's satisfaction with sex or sexual intercourse when examining female sexuality. Instead, this research encourages women to describe what is important to their unique sense of sexuality.

Critique of Masters and Johnson's Sexual Response Cycle.

Although Masters and Johnson's research was pioneering, it has received it's share of criticism (Nelson, 1997; Tiefer, 1995; Webb, 1985). Critics report that this research is a limited perspective as sexuality involves much more than the physical act of sex. Although it was not Masters and Johnson's intent, their research does not answer questions as to why and how people experience desire (Webb, 1985). In addition, Masters and Johnson's research was conducted in a laboratory and describes neat stages of sexual response and excitement, however, many sexual encounters are much more diverse than this and as a result, would not fit into their findings.

Tiefer (1995) presents a feminist critique of the human sexual response cycle. Tiefer asserts that this model of sexuality favors men's sexual interests over those of women. In addition, by simply proclaiming that men's and women's sexual responses are in fact similar, fundamental gender differences and inequalities are disregarded. Tiefer argues that the human sexual response cycle and its attempt at gender equity, actually disguises and trivializes social reality (i.e., gender inequality), and instead, makes it more difficult for women to become sexually equal. For example, men and women are raised with a different set of sexual values; that is, men toward physical

gratification, and women toward intimacy and emotional connection. The sexual response cycle focuses on intercourse and orgasm, and as a result, ignores aspects of sexuality that are important to women, such as, intimacy and interpersonal relating. In addition, the sexual response cycle assumes that men and women desire the same kind of sexual pleasure and desire and demonstrates this by reporting their identical sexual phases. However, again, sociocultural realities inform women that this is not so as men and women's sexual development and interpersonal sexual meanings are strikingly different. Women are more likely to rank affection and emotional connection as more important than achieving orgasm (Tiefer, 1995). Therefore, in this research the participants were asked to describe the sociocultural context of their sexuality. That is, women were asked to outline the messages they received from their family, peers, religious institutions, and any other sociocultural influence in order to have a greater understanding of their sexual development and to avoid any assumptions that the women have created similar sexual meanings.

Myths of Female Sexuality

There are many factors which influence sexuality. Parts of women's sexuality may be impressed upon by social influences, stereotypes, and myths. In the context of this present research, it is important to examine a few socially and culturally held beliefs and misconceptions about women's sexuality. Traditionally, there have been many mythical perceptions of women's sexuality. One of the most popular has been constructed in terms of the whore and the Madonna (Bernhard, 1995; Nelson, 1997; Northrup, 1998). Women are either seen as sexually insatiable, or pure and chaste. Women who are sexually active are usually heavily censured and labelled as whores. The Madonna myth equally denies a woman's sexuality. It labels women as nonsexual, except for the case of childbearing. However, much of society expects women to fit one of these two categories (Bernhard, 1995).

An additional myth is that women, such as nuns, older women, and disabled

women, are asexual because of their differences from other women. As is the case of the Madonna myth, this belief supposes that these women have no sexual desires or feelings (Bernhard, 1995). Another pervasive myth about sexuality is that sexuality refers only to heterosexual activities and that the highest form of sexual expression is heterosexual intercourse (Bernhard, 1995). This heterosexist notion that intercourse is the pinnacle of sexual expression disregards the idea that many women experience pleasure and orgasm through direct stimulation of their clitoris, which is quite separate from vaginal penetration. In addition, the clitoris is the primary organ of female sexual expression and is the only organ that has sexual pleasure as its only purpose (Bernhard, 1995). This myth that heterosexual intercourse is the pinnacle of human sexuality is also pervasive in the literature on breast cancer and sexuality. Current literature is performance focused as it measures frequency of male-female intercourse, desire for male-female intercourse, and other narrow notions of sexuality. These aspects of sexuality are limiting to those women who are not in relationships with men, and to women who indicate that there are other aspects of sexuality that are more important to their sense of sexuality than sex itself (Andersen et al., 1989; Margolis et al., 1990; Wilmoth & Townsend, 1995). For these reasons, participants in this research were asked to describe their personal sense of sexuality, without the assumption that sex was a necessary part of their sexuality. Also, it was important to include older women, younger women, women who are in relationships with women, and women who are not involved in intimate relationships the opportunity to describe their personal views of sexuality. As such, women with diverse backgrounds add breadth and depth to the interviews and subsequent results, and this supports the validity of the research as women with different backgrounds did share in common themes of sexuality.

Women Centered Sexuality

Recently, women have been reconstructing their own sexual identities and

describing a sexuality that is different from the traditional models of sexuality (Bernhard & Dan, 1986). Women centered definitions of sexuality differ from traditional definitions. New definitions suggest that sexuality is something created uniquely by women, not imposed upon them. Women centered sexuality is defined on the basis of what they have experienced in their own lives through feelings, experiences, relationships, closeness, and mutuality (Bernhard, 1995). Similarly, Kitzinger (1985) asserts that women's sexuality, in particular, depends on other things that are happening around women and their feelings about identity and self-worth. In other words, the context of their lives may impact their sexuality. Their work, relationships, children, friends, and other demands from the environment affect their sexual experiences and sexual identities.

> For a woman, sex is much more than whether or not she is in a sexual relationship or whether or not she is having orgasms. It has to do with the way she expresses herself through her body, with her closeness with the bodies of her children and her friends, as well as lovers. It springs from her feelings about her body as it passes through all the changes of puberty, the ovarian cycle, childbearing and menopause, through grieving and loss and into old age. It is inextricably linked with the way she gives and receives love (Kitzinger, 1985, p.26).

Similarly, Daniluk offers that "At any point in time, sexuality may be highly personal or interactive; it may be profoundly physical, relational, emotional or spiritual, and it may include a woman's body, mind, or soul" (Daniluk, 1998, p.7). Certainly, sex and sexuality are more than intercourse and orgasm. These are just small parts of women's sexuality and equating sexuality to intercourse and orgasm neglects that which makes female sexuality exciting and strong. A woman's awareness of her whole body and its functions is a large part of what separates her sexual experiences from men's. Women's sexuality as defined by women is a diffuse,

total body experience, not just the act of coitus (Bernhard & Dan, 1986). Women can experience their whole body to be sexual. Sexuality is indeed an important and a rich part of a woman's life. These rich and notably broader definitions of women's sexuality are particularly appropriate frameworks for sexuality in this current study. For the purpose of this research study, women's sexuality is thought to be a complex, contextual experience in which work, relationships, children, friends, and illness can impact on the participants' experience and definition of sexuality and their sexual identities. Kitzinger (1985), Daniluk (1998), and Bernhard and Dan's (1986) frameworks for women's sexuality seems to fit the purpose of this study by offering the potential of a broader definition of women's sexuality.

With the diagnosis of breast cancer, aspects of a woman's sexuality can be one of a larger number of life activities that are affected. However, previous research in the breast cancer field has not examined sexuality in its broadest sense. Earlier research has focused on the biological aspects of sexuality, such as the physiological responses to sexual stimulation and male-female intercourse (Andersen et al., 1989; Ganz et al., 1998; Margolis et al., 1990; Wilmoth & Townsend, 1995). Previous researchers have not examined the broader sense of sexuality in the context of women's lives, relationships, and emotions and what this might mean to breast cancer survivors. This is, in essence, what this present research will attempt to achieve. There are many factors that can influence women's sexuality. A woman who is diagnosed and treated for breast cancer may experience depression, anxiety, and a number of other emotional difficulties. These emotional difficulties could, in turn, have an impact on how she sees herself as a woman and her sexuality. This literature review examines the psychological and psychosocial responses to breast cancer and their impact on sexuality.

Psychological and Psychosocial Responses to Breast Cancer

Emotional difficulties often follow the diagnosis and treatment of cancer. This section will examine such responses as they may also inadvertently affect a woman's sense of self and sexuality. The two most prevailing affective disruptions among cancer patients are depression and anxiety. Depression and anxiety, in addition to grief, loss, anger, and fear, present major complications to satisfactory adjustment during diagnostic, treatment, or recovery periods and may delay return to previous life patterns. Researchers have reported that 17% to 51% of breast cancer patients experience significant emotional morbidity, such as anxiety and depression, before surgery (Bulman, 1992; Dean, 1987; Goldberg et al., 1992; Millar et al.,1995). As a result, it is not uncommon for most newly diagnosed cancer patients to experience anxiety or depression.

As most newly diagnosed cancer patients are older adults (National Cancer Institute of Canada, 1998), younger women with breast cancer experience more emotional distress than older women. This heightened distress in younger women has been linked to the possible infertility caused by cancer treatments. In addition, younger women who are not in committed relationships may also fear the possibility of rejection (Schover, 1994). In addition to a woman's age, the stage of the cancer at the time of diagnosis can influence psychological outcome. Researchers have reported that over time, psychosocial difficulties tend to improve among women with early stage I or II breast cancer (Bloom & Kessler, 1994; de Haes et al., 1986; Northouse & Swain, 1987). In the first few months after diagnosis, such women tended to experience more psychological distress than those women 6 to 12 months after diagnosis and surgery (Bloom & Kessler, 1994; Morris, Greer, & White, 1977). Additional researchers have also demonstrated that many cancer-related psychosocial difficulties resolve during the first year (Ganz et al., 1992; Wolberg et al., 1989). However, between 21% and 30% of women continue to experience emotional distress

one to two years after surgery (Dean, 1987; Goldberg et al., 1992; Maguire et al., 1978; Maunsell, Brisson, & Deschenes, 1992). As a result, it is evidenced by the rates of depression and anxiety that the diagnosis of a life threatening disease can challenge a woman's sense of self. As sense of self is one part of a woman's sexuality, it is therefore possible that women's sexuality is further challenged as a result of a breast cancer diagnosis. With regards to sexuality, younger women may be more concerned with reproductive issues than older women, and as a result, both younger and older women participated in this research study to obtain a broad sample of sexuality concerns. Also, participants, who had Stage I, II, or III breast cancer, were at least one year post treatment to allow for a period of time for the women to achieve some sort of normalcy in their lives.

Among the indicators of poor psychosocial adjustment are disruptions in the cancer patient's life. Disruptions to and difficulty adjusting to work changes (Schonfield, 1972; Morris et al., 1977), changes to home life and patterns (Northouse & Swain, 1987), changes in social lives and friendships (Northouse & Swain, 1987) affect psychosocial adjustment; however, it has been demonstrated that these disruptions improve over time (Zemore & Shepel, 1989). Women can experience anxiety for many different reasons. Anxiety has been linked to fears about the cancer recurring (Cawley, Kostic, & Cappello, 1990; Wong & Bramwell, 1992), fears about undetected cancer in the body (Wong & Bramwell, 1992), fear of death (Cawley et al., 1990), deciphering the meaning of physical symptoms, changes to body image, and the social stigma of cancer (Wong & Bramwell, 1992). There are many factors which influence the psychosocial well-being of cancer patients, and as a result many aspects of a woman's sexuality can also be impacted. As mentioned previously, women were at least one year post treatment to allow for a period of time to cope with the changes and disruptions in their lives caused by the cancer.

For women facing recurrent breast cancer, psychological distress is much

more common. Patients who have been told that their cancer has returned report shock and depression (McEvoy & McCorkle, 1990), anxiety and powerlessness (Chekryn, 1984), fears about death, disability, and pain (Eckleberg, Griffith, & Foxall, 1986), and a sense of injustice at the renewed assault of the cancer (Chekryn, 1984). In one study, the majority of cancer patients experiencing a recurrence said that the recurrence was more distressing than the initial diagnosis (Mahon, Cella, & Donavan, 1990). As a result of the distress facing women with recurrent breast cancer, this present study will not include women with recurrent disease. Similar to metastases, it is believed that recurrent cancer brings strong survival concerns which may overshadow thoughts of sexuality. Therefore, this research focused on women who have not had a cancer recurrence as recurrence may present unique issues and experiences not shared by other women with breast cancer.

The diagnosis of cancer can have a significant impact on a woman's sense of self and well-being. This challenge to her psychological well-being can also have ramifications for her sense of herself as a woman and her sexuality. The following section includes a descriptions of the relevant research in the area of breast cancer and sexuality.

Breast Cancer and Women's Sexuality

In Western cultures, breasts are symbolic of sexuality and femininity (Fallowfield, 1996; Ghizzani et al., 1995; Smith & Reilly, 1994). Researchers have pointed out that cancer does not have to directly involve sexual organs to impair or impact sexual functioning or a sense of sexuality (Curtis & Buemer, 1986; Wise, 1987). For example, all cancers can impact body image and self-image and may therefore affect a person's sexuality. Nevertheless, cancers that do involve body parts that are directly related to sexual functioning and cause significant body changes not only have a psychological impact on sexuality, but perhaps even a physiological

impact as well (Dobkin & Bradley, 1991; Schover, Evans, & von Eschenbach, 1987). As a result, cancer of the breast can have a significant impact on a woman's view of herself as a woman. It has been reported that many women who have been treated for breast cancer experience changes in their sexual lives (Andersen, 1984; Andersen et al., 1989; Dobkin & Bradley, 1991). For example, estimates indicate that one-third to one-fourth of women experience sexual functioning difficulties after treatment. These sexual difficulties include less frequent intercourse, diminution of sexual excitement, dyspareunia, and difficulty reaching orgasm to name a few (Andersen, 1984; Northouse, 1994). However, researchers in this area have focused on performance-related aspects of sexuality through quantitative means, and as a result, provided results limited to narrow aspects of sexuality. Therefore, this research will focus on expanding women's sexuality in the breast cancer literature towards a broader understanding of sexuality.

As women in this current research have had a variety of breast cancer treatments (i.e., surgery, chemotherapy, and radiation), an overview of the possible impact these treatments could have on sexual functioning and other aspects of sexuality will be presented in this section. First, possible psychological and psychosocial factors that may impact sexual functioning will be addressed. Next, treatment effects on sexual functioning will be covered. Within this section, more specific treatments, such as surgery and chemotherapy, and their respective effects on sexual functioning will be described.

Psychological and Psychosocial Factors in Sexual Difficulties of Women with Breast Cancer

There are many factors which may play an important role in the etiology of sexual difficulties. Sexual difficulties may result from biological, psychological, and social factors associated with cancer (Dobkin & Bradley, 1991). Subsequent sections will explore the biological and physiological aspects of sexual difficulties, such as,

the effects of surgery and chemotherapy treatments. This section will briefly discuss psychological and social factors that may impact a woman's sexuality.

Psychological functioning plays an important role in sexual functioning in breast cancer patients. As previously discussed, negative emotions such as anxiety, depression, anger, despair, and concerns with body image may suspend sexual activity and energy. Certainly, women's relationships with their bodies can impact their sense of self and sexuality. In a classic definition by Schilder (1950), body image is described as the view of one's body and its relationship to the environment. A woman's view of her body, how she perceives her body, and how she believes the public world views her body may influence her sense of self and confidence interacting with the world. When examining body image in relation to breast cancer, it is important to keep in mind that body image may not be a distinct dimension, but instead, it may overlap with sexuality; whereas both body image and sexuality fall within the broader concept of "self-image" (Hopwood, 1993).

A woman's body image is particularly important when "body integrity is breached or body function altered as a result of medical intervention" (Hopwood, 1993, p. 276) such as that associated with breast cancer. In particular, losing a breast can have profound impact on a woman's body image. As Kitzinger (1985) contends, "Losing any part of the body in a mutilating operation, however necessary and however life-saving the surgery, involves grieving. This process is long and painful for some of us. It can profoundly affect our view of ourselves and our sexuality" (p.297). When body image is threatened by mastectomy or lumpectomy, women have made comments such as "feeling a freak", "feeling half a woman", and "feeling mutilated" (Maguire et al., 1983). For women, this distress may lead to avoidance behaviors, such as, removing mirrors, dressing and undressing in the dark, avoiding taking a bath, and avoiding looking at their chest walls (Maguire et al., 1983). As is true of the sexuality literature, body image has been studied using questionnaires.

Mathieson (1994) reported that how women described their bodies and their relationships to their bodies was strikingly different from the questions posed to them on body image questionnaires. That is, women were requested to comment on concepts and questions of body image that did not fit their perceptions of their relationships to their bodies. Although this current research focuses on sexuality and not body image, the two constructs do overlap. Body image, like sexuality, is too sensitive and complex a construct to quantify. As a result, this study encourages women to describe what is important to their sense of selves as women, as opposed to projecting their experiences onto a questionnaire.

As a result of how breast cancer and its treatment can impact body image, it may be beneficial to examine how women felt about their breasts before their cancer diagnosis. Fallowfield (1996) has criticized published articles for failing to determine what the baseline sexual interest of the women was before surgery, and as a result of this, it is unclear as to whether lack of interest preceded the surgery or if it is a consequence of the diagnosis and treatment. Similarly, Schover (1991) reported that "a woman's overall psychological health, relationship satisfaction, and premorbid sexual life appear to be far stronger predictors of post-cancer sexual satisfaction than is the extent of damage to her breast" (p.113). Other researchers (Burbie & Polinsky; 1992; Dobkin & Bradley, 1991) have also reported that it is important to examine a couple's sexual relationship before the cancer diagnosis before concluding that the woman's sexual relationship aspect of sexuality has been impaired as a result of the cancer. Therefore, in this research, women were asked to discuss their sense of sexuality before they were diagnosed with breast cancer in order to provide a context for their descriptions of their sexuality since their cancer diagnosis.

Another possible psychosocial determinant of sexual difficulties may be a sense of loss of control. If a woman frequently worries about undetected cancer cells, she may become over-attentive to bodily sensations which may interfere with her

sexual activity (Dobkin & Bradley, 1991). In one research study, 45% of patients reported some degree of loss of control as a result of their cancer diagnosis. Most patients reported a feeling of loss of control over their bodies and their health. Some participants reported a loss of control over their feelings, their physical or social activities, and their future (Lowery, Jacobsen, & DuCette, 1993). However, in the research of Lowery and colleagues, women ranged from one month post-diagnosis to 60 months post-diagnosis. Certainly, women who were only a few months from their diagnosis might experience a different level of loss of control than those who were four or five years past their diagnosis. In this present research, all participants were at least one year from the time of diagnosis.

Women tend to lead complex, busy lives. For many women, concurrent life stressors, such as financial difficulties, occupational changes, or family discord may have psychological consequences. A woman who is trying to adjust to the cancer diagnosis and treatment may feel understandably overwhelmed when faced with additional work and home demands. As a result, she may experience a transient loss of interest in sex when faced with demands that are perceived as exceeding her capabilities (Witkin, 1975). Life stressors which may influence sexual functioning certainly point to the complexity of sexuality. The literature on sexuality and breast cancer fails to mention if and how work, family, and relationships can impact a woman's sense of self. Previous researchers have focused on a narrow aspects of sexuality, such as sexual performance and fails to take into account other rich, contextual factors of sexuality, such as work, family, and relationships. As a result, this current research expands the narrow definition of sexuality and explores sexuality from a broader perspective by taking into account the rich, contextual layers of women's sexuality.

Treatment Effects On Sexual Functioning

Sexuality, in its most inclusive sense, has been described as the totality of

human feelings, attitudes, and actions that people attach to their own biological sex. It is all the aspects that encompass being a male or female and is not limited to biological aspects or merely sexual functioning (Luria, Friedman, & Rose, 1987). Even with this inclusive definition, much of the research in the area of breast cancer and sexuality only focuses on intercourse and other performance-related aspects of sexuality in response to breast cancer treatment (Andersen et al., 1989; Andersen & Jochimsen, 1985; Ganz et al., 1996; Margolis et al., 1990; Schover et al., 1995; Wilmoth & Townsend, 1995).

During and after breast cancer treatment, many aspects of sexual functioning can become impaired. Burbie and Polinsky (1992) presented a four phase model which indicated aspects of sexuality which may be affected at any given stage of the cancer experience. In the "pretreatment" stage, the authors offered that sexual desire usually decreases as both the patient and partner are actively dealing with survival concerns. During "active treatment", different types of sexual problems can occur as a result of the cancer treatment. For example, Schover (1988a, 1988b) has described many ill-effects that the cancer treatment can have on sexual desire and response. The patient can experience lack of desire, pain, and sexual unattractiveness caused by hair loss, breast loss, nausea, weight loss or gain, and fatigue. Women can also experience premature menopause, yeast infections, hot flashes, and vaginal dryness that may interfere with sexual functioning. (Schover, 1988a).

The authors also realized that in the "post treatment" phase many problems persisted over time. Polinsky (1994) discovered that 50% of sexually active women who had survived an average of eight years since their breast cancer diagnosis continued to experience sexual difficulties which they believed to be a result of the breast cancer. The women described feeling sexually unattractive, having difficulty becoming sexually aroused, having difficulty achieving orgasm, and feeling dissatisfied with their level of sexual activity. However, a particular questionnaire

used in this research was developed by the author and the psychometric properties had not yet been investigated. Also, the women studied were more knowledgeable than the average breast cancer survivor as they were trained to be Reach to Recovery volunteers. As a result, the research results can only be generalized to other Reach to Recovery volunteers in southern California.

In the "recurrence" phase, being diagnosed again with cancer was an overwhelming experience; often more overwhelming and terrifying than the initial diagnosis (Mayer, 1997). As a result, the patient may experience a lessened sexual desire while she faces the disease and focuses on survival. (Burbie & Polinsky, 1992). Again, this four phase model describes only sexual performance aspects of sexuality. Unlike the purpose of this current research, Burbie & Polinsky (1992) neglected to examine other psychosocial aspects of sexuality that are important, such as, relationships, intimacy, and personal meanings and experiences of sexuality.

In another recent study (Ganz et al., 1996), 70 breast cancer survivors were surveyed 2 and 3 years after their initial surgery to inquire as to their psychosocial concerns and quality of life. The authors reported that not only does sexual functioning (i.e., measure of interest and performance in sexual activity) fail to recover during the first year of treatment, it actually continued to deteriorate further in the second and third year after the initial cancer surgery. In addition, nearly half of the sample still reported body image problems, and sexual problems were described as very frequent and severe in intensity. Forty percent of participants who reported a decrease in sexual interest related this to feelings of sexual unattractiveness. Ganz and colleagues (1996) hypothesized that a major reason for the lack of recovery of sexual functioning during the first year after surgery was a result of the psychological trauma of the diagnosis and breast cancer treatment. That is, the women would need some time to recover and adjust to such a shocking diagnosis and threat to their lives. As a result, the authors expected that sexual functioning would recover in the second

and third years and were surprised when it actually further declined. These research findings suggest that the sexual problems related to breast cancer treatment may not be as transitory as one would hope (Ganz et al., 1996; Morris et al., 1977; Polinsky, 1994). The results suggested that a time factor could explain some of the variance seen in the prevalence rates for sexual difficulties in cancer patients (Dobkin & Bradley, 1991). In this present study, breast cancer survivors will be at least one year post treatment so as to give women time to adjust to their diagnosis, treatment, and recovery, and time to achieve a sense of normalcy.

Mastectomy versus breast conservation and impact on sexual functioning.

As presented above, breast cancer treatment can interfere with many aspects of sexual functioning. However, research has noted that specific breast cancer treatments can have specific effects on women's sexuality. For example, many women describe the occurrence of mastectomy as a mutilating and disfiguring experience (Harwood & O'Connor, 1994). Increasingly, due to similar survival rates, women with early stage breast cancer are offered lumpectomies instead of mastectomies as a treatment option. The fundamental objective for offering women this alternative is to preserve the integrity of women's body image (Harwood & O'Connor, 1994), thus having a more positive consequence on this aspect of sexuality.

Considerable quantitative research has investigated the effects of lumpectomy and mastectomy on female sexual behaviors (Ganz et al., 1992; Margolis et al., 1990; Kiebert et al., 1991; Margolis et al., 1989; Mock, 1993; Schover, 1991; Schover et al., 1995; Wellisch et al., 1989; Wilmoth & Townsend, 1995; Wolberg et al., 1989). Although, some researchers believe that the less mutilating surgery has fewer negative sexual effects (de Haes et al., 1986; Hall & Fallowfield, 1989; Holmberg et al., 1989; Margolis et al., 1989), the literature regarding the impact of breast conserving surgery on all aspects of sexuality is contradictory and conflicting.

Through quantitative means, Ganz and colleagues (1992) and Wilmoth and Townsend (1995), attempted to demonstrate that there are few differences between lumpectomy patients and mastectomy patients on measures of sexual functioning. Using the Sexual Behaviors Questionnaire and the Watts' Sexual Functioning Questionnaire, Wilmoth and Townsend's research investigated the effects of lumpectomy and mastectomy on female sexual behaviors with a sample of 165 women. These measures of sexual behaviors contain items that refer to the three phases of the Sexual Response Cycle (i.e., desire, arousal, and orgasm) as well as to overall sexual satisfaction. Their results indicated that no significant differences exist between women treated by lumpectomy and those treated by mastectomy on measures of sexual behavior. The authors asserted that the findings were significant in that they suggested that the perceived sexual benefits of the less disfiguring surgery on sexuality may not have occurred. However, the researchers' focus on sexual behavior offers a narrow view of one aspect of women's sexuality, and consequentially, this present research explores a broader definition and experience of sexuality which cannot be captured with questionnaires.

With similar results to Wilmoth and Townsend (1995), Ganz and colleagues (1992) evaluated problems related to interest and performance in sexual activity in 109 women with early stage breast cancer. One year after surgery, no statistically significant differences in the measure of sexual functioning were found between the two surgical groups. However, patients who had lumpectomy had fewer problems with body image and problems with clothing, that is, feeling comfortable in certain clothing and finding appropriate clothing. Body image scores improved significantly for both groups during the year of observation which would suggest progression and adjustment to the effects of the surgery (Ganz et al., 1992). Again, questionnaires were used to obtain a limiting, performance-based perspective of sexuality. Perhaps there were no significant differences between the two surgical groups because the

participants were diagnosed with early stage breast cancer, and as a result, this influenced how they felt about themselves as women and sexual beings.

The results of three particular studies reported that lumpectomy patients report less negative feelings about their body and other aspects of their sexuality. For example, Mock (1993) compared body image in 257 women who received either mastectomy, mastectomy with delayed breast reconstruction, mastectomy with immediate reconstruction, or lumpectomy through the use of questionnaires. Results indicated that the lumpectomy group had significantly higher body image scores than both the mastectomy group and the immediate reconstruction group. However, the validity of the results are questionable as one of the instruments was developed by the author, and as a result, there were no data on the reliability and validity of the instrument. In addition, women were recruited who had completed treatment anytime between two months and two years. Perhaps the significant difference between the groups could be a result of the short time which had elapsed since treatment was complete. Some women were only a few short months post treatment, and perhaps those women with mastectomies or mastectomies and reconstruction need more time to adjust to the changes to their bodies. It would be interesting to revisit these women and re-examine the results when all the participants are at least two years post treatment. In this current research, all of the participants are at least 1 year post treatment to allow time for healing and resuming their "normal" lives.

Body image and sexuality were assessed in 50 breast cancer patients who were on average 21 months post-treatment (Wellisch et al., 1989). The patients had undergone mastectomy with breast reconstruction (n=15), mastectomy without breast reconstruction (n=13), or lumpectomy (n=22). Results indicated that lumpectomy patients reported feeling significantly less negative about their nude appearance than did the patients in the other two groups. In addition, lumpectomy patients were significantly more likely to report that they felt good about their bodies and felt less

shame than patients who had undergone a mastectomy without reconstruction. Also, lumpectomy patients were significantly more likely to feel that their body looked as it did before breast surgery. Women who had undergone a mastectomy, with or without reconstruction, reported feeling less sexually desirable after surgery than the lumpectomy patients. As a result, the lumpectomy patients appeared to have a better body image. However, it is important to exercise caution when interpreting these results due to the small sample size. In addition, one of the instruments employed was designed by the authors and there were no data on the validity or reliability of the test.

Studying the psychosocial effects of lumpectomy and mastectomy, Margolis and colleagues (1990) reported that patients that had lumpectomy (97%), felt as attractive after treatment as they had before treatment. However, most mastectomy patients (78%) felt less attractive. When undressed, all mastectomy patients felt badly and more ashamed about their bodies, while lumpectomy patients reported positive feelings. Mastectomy patients also felt less sexually desirable following surgery, while lumpectomy patients generally experienced no change. Although lumpectomy and mastectomy patients did not differ on the frequency of sexual activity before or after surgery, lumpectomy patients gave significantly higher ratings to the quality and level of enjoyment of their sexual relationships than mastectomy patients (Margolis et al., 1990). However, it is important when interpreting results to understand that there were only 32 patients in the lumpectomy sample and 22 patients in the mastectomy sample. Also, Margolis and colleagues could not find a suitable instrument and so created their own measures. Again, no data on the validity or reliability of this measure were reported. It is also important to note that the authors utilized questionnaires to explore sexual performance aspects of sexuality, such as sexual desire and sexual performance. This current research explored a more comprehensive view of women's sexuality.

In a review of 18 studies that researched the impact of lumpectomy and mastectomy on the quality of life of breast cancer patients (Kiebert et al., 1991), sexual functioning was investigated in 11 studies. No differences were found in seven of these studies. The difference found in the other four studies were all in favor of the breast-conserving surgery. More difficulties (Beckmann, Johansen, & Richardt, 1983; Steinberg, Juliano, & Wise, 1985), later resumption of sexual activities, including intercourse (Beckmann et al., 1983; Taylor, Lichtman, & Wood, 1985), changes in breast stimulation, talking less openly about sexuality (Steinberg et al., 1985), and less satisfaction with and frequency of sexual experiences (Wolberg et al., 1989) were noticed after mastectomy. These investigations included narrow, performance-based aspects of sexuality that were studied through the use of questionnaires.

Wilmoth & Townsend (1995) offer explanations as to why researchers have not shown more significant differences between mastectomy and breast-conserving surgeries with regards to sexual sequelae. They hypothesized that the lack of significant findings may have been caused by the lack of sensitivity of the quantitative measures to changes in sexuality caused by breast cancer surgery. Conducting this research within a qualitative framework allowed the participants to describe any changes they have experienced in their sexuality without having to project their experiences onto a questionnaire which may lack sensitivity to subtle changes in sexuality. As reports on the impact of lumpectomy and mastectomy on sexuality seem to be somewhat conflicting, this current research presented the experiences of women who have had either mastectomy or lumpectomy. As a result, women with different experiences provided depth and breadth to the shared common themes.

Sexual side-effects of chemotherapy.

Not only may a mastectomy or lumpectomy impair a woman's body image

and sense of self, but the side-effects of adjuvant chemotherapy can be much more destructive than the surgery itself (Schover et al., 1995). Chemotherapy can impact many aspects of sexuality, such as arousal, sexual response, and body image. For example, chemotherapy side-effects often include fatigue, lethargy, depression, nausea, vomiting, hair loss, and weight gain among others. A woman who has lost her hair, experiences fatigue, and has gained weight will not likely feel sexually desirable or sexually excited, especially as these side-effects occur only a few weeks after she has lost her breast(s). These difficult side-effects may be more severe for women who do not feel secure in their relationships, or when the side-effects reawaken pre-existing sexual problems. In one particular quantitative research study, breast cancer patients who had received chemotherapy reported a significantly poorer body image, had sex less frequently, had more vaginal dryness, less able to achieve orgasm, and rated their sex lives as less satisfying than women who did not have chemotherapy (Schover et al., 1995).

Although the chemotherapy side-effects may be made more tolerable because they are time-limited and reversible, there are many commonly used chemotherapeutic agents which can also do severe harm to women's sexual functioning that may be indeed irreversible. More specifically, the alkylating drugs such as cyclophosphamide and phenylalanine mustard, and adriamycin are likely to impair fertility and menstruation, and these drugs can also adversely effect sexual functioning and sexual desire by interfering with the production of sex hormones (Kaplan, 1994). Although these reports address the effects of chemotherapy on the sexual functioning aspects of sexuality, it is unclear as to how chemotherapy may effect psychosocial aspects of sexuality. This research provided women with the opportunity to explore the effects of breast cancer treatment on psychosocial aspects of sexuality. For the purpose of this research, not all women had adjuvant chemotherapy as a part of their treatment plan. Having diverse experiences with

cancer treatments allowed the researcher to compare experiences and look for patterns across a variation of experiences.

Conclusion

The literature that has been discussed thus far has provided physicians, mental health professionals, and breast cancer survivors with critical information about sexual performance aspects of sexuality. Researchers have broadened our knowledge as to how breast cancer treatment can impact a woman's desire for intercourse, pleasure in intercourse, and her ability to achieve orgasm. This wealth of research has also enabled women to make informed decisions by weighing the consequences of mastectomy or breast-conserving surgery. Expanded knowledge concerning the sexual side-effects of treatment, most notably chemotherapy side-effects, has improved women's treatment and offered some possible remedies (Kaplan, 1994).

Nevertheless, the literature on breast cancer and sexuality offers a narrow and constricting view of women's sexuality. Intercourse between men and women, the frequency of intercourse and the sexual response cycle are mere aspects of sexuality and this interpretation of sexuality neglects additional significant aspects that women may find important, such as, affection, emotional connection, relationships, and other contexts of women's lives. As a result, this current research attempts to describe the meaning and experience of sexuality to breast cancer survivors. Women's sexuality must be described and identified by women based on their own experiences and feelings so that a fuller expansion of women's sexuality can be defined. Scholars in women's sexuality report that women's sexuality is a much more complex phenomenon than the act of intercourse and other performance-based aspects of sexuality (Daniluk, 1993; Kitzinger, 1985). However, it is this narrow view of sexuality that has been the focus of the literature on breast cancer and sexuality. Furthermore, these findings have been obtained largely through quantitative means

with questionnaires which lack the sensitivity required to study sexuality. As a result, this present qualitative research provides women with an opportunity to describe in great detail their personal sense of sexuality. A broader definition of women's sexuality will greatly add to the literature on breast cancer and sexuality.

CHAPTER THREE
METHODOLOGY

I also hope to suggest that the data...(is) in the stories of the women who live and die with cancer--stories of strength and transformation that are cloaked by the statistical analysis through which we usually explore this phenomenon.

M. Bricker-Jenkins, 1994, p.17

Present Research

Most of the previous literature has described the effects of breast cancer on sexuality in performance-based terms; such as, frequency of intercourse, desirability for intercourse, and frequency of orgasm. However, scholars who study women's sexuality assert that sexuality is more than the act of intercourse (Daniluk, 1998; Kitzinger, 1985). As a result, in this present research, women described their personal experiences of sexuality and how it relates to breast cancer. It was not assumed that their experience of sexuality would be limited to intercourse with men, but instead, women were given the opportunity to express their own unique sense of sexuality. This research attempted to understand a woman's experience of sexuality from her own point of view and she was encouraged to tell her story in any way that she chose. An open-ended interview approach was chosen since questionnaires that have previously been used to examine aspects of women's sexuality have focused on narrow aspects of sexuality, such as intercourse and frequency of coitus (Franzoi & Shields, 1984). They are limited because women's perceptions and meaning of sexuality may be too sensitive and too subtle to be elicited by fixed-choice (Hall & Fallowfield, 1989), or forced-choice, questionnaires in which women choose a

response that is "closest" to their experience, but does not truly represent their experience. In Mathieson's (1994) research with body image, she maintained that women's own stories bore little resemblance to the type of questions which were posed on body image questionnaires. Furthermore, she concluded that "had I stuck with standardized questionnaires only, I would have had body image scores which in no way address the meaning of body changes of women with cancer" (p. 16). Mathieson is not convinced that numerically driven approaches would have allowed her to understand the disparity between what the patient says about her experience and what research tells us about the patient's experience. As a result, women were encouraged to describe their sexuality and the impact breast cancer had on this aspect of their lives through in-depth interviews which allowed for a more open, expanded view of women's sexuality.

Qualitative Methodology

Qualitative research emphasizes meaning and understanding of an individual's experience with a certain experience in a way that cannot be captured with questionnaires. There are certain features of qualitative descriptive methodology, or human science research, that separate it from the more traditional, natural science, quantitative research methodologies (Moustakas, 1994). Firstly, human science research recognizes the value of qualitative methodologies for studies involving human experience that are not approachable through quantitative means. Also, Moustakas asserts that qualitative research focuses on the "wholeness of experience" rather than only on its parts. Thirdly, qualitative research searches for meaning and "essences of experience" instead of measurements and explanations. In addition, human science research creates questions and problems that mirror the interest and involvement of the primary researcher. Lastly, qualitative research views the experience as an "integrated and inseparable relationship of subject and object and of

parts and whole" (Moustakas, 1994, p.21).

Qualitative descriptive methodology acknowledges that people construct their own meaning in relation to the world in which they live. Qualitative descriptive research explores and reflects human experience in the way in which it is uniquely and inherently encountered. As Boyd (1993) noted, qualitative researchers acknowledge that people construct their own meaning in relation to the world in which they live:

> Qualitative researchers direct their attention to human realities as opposed to the concrete realities of objects. The distinctive valuing of and respect for people in qualitative research do not allow for their objectification as featured in quantitative research. People are thus centered in qualitative research in recognition that reality is constituted in human perspectives. (Boyd, 1993, p.79)

As a result, this methodology used personal descriptions of how the phenomenon under investigation had impacted individuals, and as a result, provided a greater, and more complete, understanding of how women's sexuality was impacted by breast cancer (Boyd, 1993). Qualitative descriptive researchers may ask, "What is this or that kind of experience like?" (van Manen, 1997). This methodology used a format that empowered the women to tell their stories in their own language without sanction. It is especially suitable for the examination and study of meanings and experiences about which little is known (Colaizzi, 1978; Daniluk, 1993; Osborne, 1990). As this research was conducted to produce a comprehensive and rich depiction of the meaning of sexuality to breast cancer survivors, it was felt that a qualitative descriptive methodology was the most suitable method.

The Question

"How do women experience and describe their sexuality after breast cancer?"

This research explored the meaning of sexuality to breast cancer survivors. The researcher explored women's personal views of sexuality before their cancer diagnosis and then the subsequent meaning of sexuality after their cancer diagnosis. Through in-depth interviews, the researcher asked women about their views on sexuality and what sexuality means to them. Also, important early learnings and early messages about sexuality were explored so that their views of sexuality and the possible impact breast cancer may have on women's sexuality can be examined through the women's own perspectives and personal contexts. There was an essential understanding in this research that a woman's own view of her sexuality is personal, unique, and individual. As such, it was important to understand their history and past learnings about sexuality before their breast cancer diagnosis and subsequent treatment to have a better understanding of the impact that sexuality may, or may not, have had on their sexuality. Open-ended, non judgmental questions were presented (see Appendix A, General Interview Guide) to the participants for their reflection.

Presuppositions

Since I am completing a Ph.D. in Counselling Psychology, an important aspect of choosing to pursue this research within a qualitative descriptive framework was the compatibility of qualitative research with counselling psychology. Qualitative descriptive methodology allowed me to remain close to the experience of the participants in a similar manner as a counselling session allows me to intimately view a client's world (Osborne, 1990). In fact, researching within a qualitative descriptive framework actually requires that researchers have personality characteristics and skills comparable to those of counsellors. That is, the capacity for empathic understanding and communication is as crucial in a researcher-participant relationship as it is in a counsellor-client relationship. Just as a counsellor is permitted to be a part of the client's experience and see part of their world, the

researcher is also permitted to be a part of the participant's experience as well (Osborne, 1990). Osborne also relates that personal qualities such as warmth, caring, openness, positive regard, ethical integrity and responsibility are equally important for counsellors as they are for qualitative researchers. Both are prerequisites for understanding the "life-world" of another.

Qualitative descriptive methodology recognizes the presence of the researcher in the formulation of the question, the determination of what are the data, the collection of that data, and the subsequent interpretation (Osborne, 1990). As experimental designs can eliminate and avoid such influence through the design of the research, qualitative researchers attempt to articulate their predispositions and biases through a process of bracketing by putting aside their presuppositions as best they can. As a result, this new awareness allows the researcher's biases to be suspended and allows for a fresh immersement in the experience of the participants (Wertz, 1984). The following is my attempt to bracket any bias and to show the reader how my experiences have shaped this research. Bracketing, or making my beliefs and expectations explicit, reduces the risk of projecting my personal bias onto the interpretation of the research interviews. This allows for an interpretation based on the interviews themselves as opposed to an interpretation based on my personal biases and predispositions.

My interest in this area has grown from personal and academic experiences. For the past 3 years, I have been involved in psychosocial oncologic research at a cancer facility in Edmonton. We have been conducting research in the area of body image and breast cancer. I also completed my pre-doctoral internship at this same cancer facility from September of 1997 to September of 1998. I interviewed the eight participants prior to the internship and completed the analysis during the internship year. From my research and internship involvement, I have heard women express their interest and personal concern in their body image and changes in sexuality since

their breast cancer diagnosis and treatment. Some breast cancer patients have attempted to discuss body image and sexuality issues with their physicians and other health care professionals, however, they reported that most professionals are uncomfortable discussing such issues. As a result, the patients have been left disappointed by the lack of support and information that they receive. It is partly because the information available to women about body image and sexuality is sparse and because there are women interested in this aspect of the disease that I have chosen to research this area.

I also held certain beliefs and expectations about the effects of breast cancer on women's sense of sexuality. As breast cancer occurs in a part of the body that has often been sexualized by our society and culture, I believed that this can create an atmosphere for potential body image and sexuality concerns. In addition, after reflecting on previous literature on breast cancer and sexuality, it struck me how the literature focused on performance-based aspects of sexuality. It was my expectation that women I interviewed would describe additional aspects of sexuality that went beyond intercourse and orgasm. I anticipated that women would discuss broader concepts of sexuality. For example, I expected that women would discuss how their sexuality has changed or evolved throughout their lives, that sexuality was a dynamic concept that was impacted by their work, family, society, and that sexuality was possibly changed as a result of a life-threatening disease.

Breast cancer effects all of us. Almost everyone knows someone who has had or is currently fighting breast cancer. I am not an exception. My maternal grandmother and maternal aunt have both had mastectomies and adjuvant chemotherapy and radiation. Currently, they are both healthy and very active, particularly active now as the Christmas season is upon us and they busy themselves with crafts and Christmas planning. As I sit in my study at home writing this chapter, my present thoughts are with my paternal grandmother who was diagnosed and

treated for breast cancer about 6 years ago. She has most recently been told that the cancer has metastasized into her liver and bones. I am going home to spend some time with her. So, although I myself have not had breast cancer, I have been touched by its effects and it is in my realm of experience.

Selection of Participants

In qualitative research, the number of participants needed is quite variable. Usually, the researcher utilizes as many participants as needed to get a full and rich description of the phenomenon (Wertz, 1984). Inclusion criteria for the participants were having the experience of breast cancer, and being willing to discuss their experience at length with the researcher. An additional criterion was that participants had been finished with treatment for at least one year. Research has shown that more women reported sexual difficulties at 12 and 24 months post-surgery than at three months post-surgery (Dobkin & Bradley, 1991). It may be hypothesized that women who have more recently completed treatment are focused on survival issues, such as concentrating on life, and are not considering sexuality to be of importance when their lives are hanging in such a precarious balance. However, when cancer treatment is completed and women are attempting to establish some sort of normalcy, sexuality may become an integral component of her quality of life. As a result, women who were approximately one year post-treatment were sought for this research as sexuality may be an important aspect of their quality of life once issues of survival have been addressed and women have achieved a sense of normalcy in their lives.

Further criteria required that the participants be free of cancer recurrence and metastases, as this may create further survival issues for women, and as a result, women may not be focused on issues of sexuality. Also, the participants may have had either a lumpectomy or mastectomy, and may have had adjuvant chemotherapy and radiation or no adjuvant chemotherapy nor radiation treatment. As this research

attempted to provide an expanded definition of women's sexuality, and it was assumed that women were sexual beings regardless of age or partnership status, women who were interested in participating could do so as long as they were of the age of consent (18 years). Similarly, it was hoped that there would be a range of relationship experiences in this research. Women could have been single, married, divorced, widowed, partnered, heterosexual, or homosexual. As a result, the participants in this research represented a diversity of cancer experiences and sexuality experiences. As such, commonalities and differences were explored within this range of experiences.

When looking for potential participants for this research, the researcher met a woman who had been diagnosed with breast cancer a number of years ago and who was willing to participate. This participant spoke to other breast cancer survivors about the research and asked if they would be interested in participating as well. The researcher gave the participant a copy of the study description (see Appendix B) which she in turn provided to other women. As a result, the researcher received the names and numbers of women who were willing to participate. The researcher contacted interested individuals by telephone and a short interview was conducted to assess whether they fit within the inclusion criteria. The four women whose names and numbers the researcher received were indeed eligible for participation and an interview was then arranged.

In addition, in the summer of 1997, the researcher was teaching at an eastern Canadian university and telephoned a provincial breast cancer organization. A member of the organization sent study descriptions (see Appendix B) of the research to members of the organization. As a result, approximately eight interested women contacted the researcher directly by telephone. Of these eight women who contacted the researcher, four did not participate either because they did not fit the criteria or because they declined participation in the study upon learning about the research

method and purpose of the study. They reported that although they were interested in the topic, they were not comfortable participating in an interview. For the remaining four volunteers who did fit the criteria and who decided to participate, a mutually agreed upon time and location for the interview was established.

Procedure

When each participant was contacted, she was informed about the purpose of the research, and the time commitment required for the study. If she expressed interest, the initial interview was arranged. It was believed that the interview was the most fruitful way of attaining a rich depiction of the phenomenon (Becker, 1986), and as a result, each participant was involved in an individual interview. Six of the interviews took place in the participants' homes, while two interviews took place in the researcher's home as it was more convenient for the two participants. The interview was open ended and minimally structured as possible to allow the participants to present their experiences as inherently and freely as possible. This format was used as it avoided both directing the participants' thoughts and asking questions which might have supported the researcher's own biases.

Prior to the actual interview, time was spent going over the purpose of the interview, and the aim of the study was discussed in more detail (see Appendix B). The researcher shared her background with the participants and answered any questions they had about the researcher or the study itself. In addition, informed consent, confidentiality, and the participants' rights to withdraw from the study were also discussed at this time (see Appendix C). Prior to the interview, demographic data were gathered as to participants' age, relationships status, employment status, and relevant information on stage and treatment of the breast cancer (see Appendix D). Ethical approval for the study had been previously obtained from the researcher's educational institution.

Care was taken to establish rapport with the participants as it is one of the most important considerations in qualitative methodology. Rapport and an atmosphere of mutual trust and respect was needed to allow the participants to provide genuine descriptions of their experiences (Osborne, 1990). In such an environment, the participant felt free to share the richness of her experience.

The initial interview began by asking "Some people have a story to tell about their sexuality, or a certain experience that they tell to help describe their experience of sexuality, what comes to mind when you think about sexuality?" The researcher followed the dialogue of the participants and requested clarification or elaboration when necessary. Additional questions were utilized as probes to prompt the participants when it appeared that they had exhausted a certain aspect of their experience (see Appendix A). The interviews were between 45 and 75 minutes in length. All interviews were tape recorded and transcribed with the permission of the participants. Based on the interviews with these eight women, it was believed that the data collected were sufficient in illustrating the essential aspects of this phenomenon, and a result, additional women were not sought to participate. After the analysis of the transcripts, the researcher contacted the women and gained permission to mail the analysis and themes to the participants for their review. About three weeks later, the researcher contacted the participants and inquired as to whether the analysis fit with their experience. This served to validate the analysis by allowing the participants to concur with or refute the researcher's interpretation.

Description of Research Participants

For the purpose of the research, eight women were interviewed who had been diagnosed with breast cancer, were at least one year post-treatment, were over the age of 18, had no metastatic disease, and were considered to be in good health. These participants ranged in age from 37 to 68 at the time of the interviews. The average

age of the participants was 50.5 years old. Six of the women were married and two of the women were divorced but were involved in intimate relationships at the time of the interview. With respect to their level of education; one participant had some college education, two women completed a college program, one participant completed some university training, two women completed an undergraduate degree and two participants completed a Masters level degree. The women in this study were, therefore, well educated.

Five of the women described themselves as working full-time (over 15 hours/week), while two women reported that they were retired, and one woman was not working due to illness. Participants were employed in a variety of field; such as, education, civil service, nursing, and community relations. The participants also described their partners' employment status as well. Four women indicated that their partners were working full-time, two partners were working part-time (up to and including 15 hours/week), and two partners were retired at the time of the interviews. Partner occupations ranged from civil service employee, lawyer, farmer, and university administrator.

Seven of the women lived with their partner while one woman lived alone. All but one participant had children, and two participants had children still living in their home. In regards to their perceptions of their overall health, 4 participants cited their health to be in "excellent" condition, one participant said her health is "very good", and three participants reported their health to be in "good" condition.

The length of time since the participants breast cancer diagnosis varied considerably. The mean length of time since diagnosis was 5.7 years with the range of time from as recent as 1.5 years to as long as 16 years (16, 9, 9, 3, 2.5, 2.5, 2, 1.5 years). Also, participants received varied types of treatment. All participants underwent surgery, with three women receiving lumpectomies and five women receiving mastectomies. Two participants received surgery, chemotherapy, and

radiation therapy in their treatment program, whereas three participants received radiation and surgery for their cancer treatment regime. One participant underwent surgery as her form of treatment and two participants received a combination of surgery and chemotherapy. In addition, one of the participants who underwent surgery and chemotherapy also received a bone marrow transplant as part of her treatment plan. Although the bone marrow treatment would suggest that Elizabeth received a poorer diagnosis and prognosis than the other participants, she was included in this study as she felt she was in good health and presented as an enthusiastic participant with much to offer this research. As with the initial diagnosis, the length of time since their treatment had been completed was quite varied. The mean treatment completion date was 5.3 years prior to the study with the range of time from as recent as 1 year to as long as 16 years.

Data Analysis

The goal of qualitative research is to reveal and unravel the structure and interrelationships that are obtained in the phenomenon under investigation (Polkinghorne, 1983). The focus is on the deep structure of meaning instead of the surface structure of the interview. Unlike a quantitative researcher who looks for structures based on a preconceived theory, a qualitative researcher looks for structures to present themselves (Osborne, 1990). More specifically, the purpose of this research was to glean from the interviews a description of the integral qualities of the experiences of breast cancer survivors in relation to their sexuality. The researcher analyzed the interview transcripts based on Colaizzi's (1978) method. The procedural steps utilized in this research can be outlined as follows.

1. Each participant's protocol, or written transcript, was read and reread in order to acquire a feeling for and to become absorbed in the descriptions of the experiences of the women.

2. Phrases or sentences were extracted from the protocol that directly pertained to the women's experiences with sexuality. This procedure is known as "extracting significant statements" (Colaizzi, 1978, p. 59). Repetitions and statements which referred to the same aspect of the phenomenon were omitted.

3. Establishing meaning from the extracted sentences or phrases, or "formulating meanings" (Colaizzi, 1978, p. 59) was accomplished through transforming the phrases as they appear in the protocol into the words of the researcher. The meaning was extracted from the phrase or statement and the researcher was left with meaningful or significant statements which reflected the essential point of each of the original statements.

> This is a precarious leap because, while moving beyond the protocol statements, the meanings he (i.e., the researcher) arrives at and formulates should never sever all connections with the original protocols; his formulations must discover and illuminate those meanings hidden in the various contexts and horizons of the investigated phenomenon which are announced in the original protocol. (Colaizzi, 1978, p. 59)

This allows the researcher to move beyond the women's statements and discover the latent meanings in their descriptions of their experiences of sexuality and breast cancer. As such, themes were created which captured the spirit of the particular excerpt. These themes were recorded beside the significant statements. Analysis included recognizing important sources and experiences that helped define their experience of breast cancer and sense of sexuality. Careful attention was paid to the context because "meanings are contextually grounded" (Mishler, 1986, p. 117). As a result, meaning may be lost when the context is removed. This procedure of extracting significant statements and creating themes was repeated for each of the eight women.

4. At this point, repetitions and irrelevant descriptions which were initially

included were eliminated. The statements and themes for all eight women were pooled together and sorted into clusters of themes. These clusters were given a name and formed the first order themes. These first order themes were in turn grouped or clustered together and formed second order themes. These second order themes reflected the women's shared meanings and experiences of sexuality in relation to breast cancer (Daniluk, 1993). This pooling and clustering of the themes of the eight women.

Although it was important that this final structure of shared experiences be shared by all eight women, it was not necessary that all aspects of the structure be reflected in each of the participants' description. However, if most of the participants described similar aspects of a theme, then the researcher inquired as to whether the other participants experienced such a phenomenon, or whether the omission in their experience had some important significance (Osborne, 1990).

5. The clusters of themes were referred back to the original protocols to validate the meanings of the themes, the clustering of the themes, and the clustering of the second order themes. This was achieved by inquiring whether there was anything in the protocol which was not accounted for in the themes, or whether the themes themselves implied a certain meaning which is not present in the protocol itself. Exceptions and discrepancies were noted and compared to the thematic structure to examine whether they fit or did not fit.

6. The final validating step was achieved by returning to each participant and presenting to her the final thematic structure. This was necessary in order to verify, or validate, how the results of the analysis compared to her experiences. If necessary, any new data or adjustments were discussed and changes or additions were made to the existing thematic structure. The participants responded very positively to the analysis and felt that it was an accurate representation of their experiences.

Trustworthiness: Credibility and Transferability

In qualitative research, trustworthiness is obtained when credibility and transferability are achieved. Credibility, or validity, is concern with establishing the truth and understanding of a specific phenomenon (Leininger, 1985). Usually, a central thematic framework will emerge (Glaser & Strauss, 1970) during the data collecting stage which will suggest possible categories and theory links. According to Guba and Lincoln (1989), credibility occurs when the results present a faithful description and account of the participants' experience of the phenomenon. Patton (1990) asserts that credibility often depends to a great extent on the methodological skill, sensitivity, and integrity of the researcher.

To increase the probability that credible findings would be produced, the researcher asked each of the participants to review the thematic analysis and comment on the accuracy of the analysis with their own experience. More specifically, in May of 1998, the researcher mailed a copy of the thematic analysis, including illustrative quotations from the interviews, to each of the participants. The participants were requested to read through the analysis and provide feedback to the researcher. Paper with addressed and stamped envelopes were provided with the analysis. It was hoped that the interpretations offered by the researcher would be reflective of the participants experiences. In June of 1998, the researcher conducted follow-up phone calls to each of the participants and inquired as to their perceptions of the analysis. Each of the participants agreed that the analysis was an accurate reflection of their experience. One woman said, "I love it...You did a great job on your project--I think you've really captured the essence of what breast cancer survivors experience...you nailed it". Other comments were, "The women have similar private thoughts...I thought I was the only one thinking it...it reaffirmed me. I was pleased to read how important it is for others", and "I thought your summary analysis was right on".

Following the telephone interviews, two women elected to provide further feedback in the form of letters. The feedback provided in these two letters was reflective of the follow-up telephone interviews conducted with the participants. The women expressed in writing that the analysis reflected their experiences.

In qualitative research, findings are not generalizable since they are closely related to a specific time, place, and person; that is, a specific context. However, the findings may be transferable to a similar setting. Transferability depends on the degree of similarity between the actual setting, the study population, and the readers. This research provided a description necessary to enable someone interested in making such a transfer. For example, a clinician or breast cancer survivor who reads these findings and feels that they can transfer these findings to themselves as a breast cancer survivor or to the population with whom they work can do so if they feel it fits with their own or their clients' experiences. Qualitative research studies are not intended to be replicable in the traditional quantitative sense. As they are colorful, context-bound descriptions, they are considered unique to that particular study sample.

Chapter Four presents a narrative synthesis of the thematic structure punctuated with salient quotations from the original protocols used to illustrate the inherent meanings of the themes. This thematic analysis is considered to illuminate the meaning of sexuality for breast cancer survivors.

CHAPTER FOUR

RESULTS

The women who shared their experiences with breast cancer and sexuality have provided this research with many rich descriptions and personal narrations. Before their experiences are described, a brief description of the participants is presented below. Subsequent to this description of the eight women, an overview of the themes is presented. Following this overview, the themes are described in greater detail and are punctuated with salient quotes pulled from the women's interviews.

Jane is a 56 year old woman who is living in the greater Edmonton area. She and her family had immigrated to Canada from Great Britain a number of years ago. She works full-time in the field of community relations. Jane is married and she and her husband have three adult children. Jane was diagnosed with breast cancer in December of 1994. She underwent surgery (mastectomy), chemotherapy, and radiation and completed this treatment in December of 1995. She considers herself to be in "good" health.

Beth is a 60 year old woman who was born in Europe and lived in Africa before moving to Canada. She is married and retired from working full-time in a school system in Edmonton. Her husband works in the legal field and is currently working part-time. They have two adult daughters. Beth was diagnosed in June of 1981 and underwent surgery (mastectomy) and radiation therapy. Her treatment was complete in July of 1981. She now considers herself to be in "excellent" health.

Lynn is a 45 year old Edmonton woman who works full-time in an administrative position in the school system. She and her husband, a university administrator, have a 10 year old son who lives at home with them. Lynn was diagnosed in September of 1994 and underwent surgery (lumpectomy), chemotherapy, and radiation therapy. Her treatment was complete in June of 1995.

Currently, she describes her overall health as "excellent".

Marg is a 52 year old woman who works full-time in the Edmonton area in post-secondary education. She is divorced and has two adult daughters. Her partner works part-time as a "jack of all trades". Marg was diagnosed with breast cancer in April of 1988 and had surgery, a mastectomy, to treat the disease. She considers herself to have "very good" health.

Barbara Anne is a 68 year old woman from Prince Edward Island who is a retired school teacher. Her husband is also retired. Barbara Anne and her husband have three adult children, one of whom is deceased. Barbara was diagnosed in August of 1988 with breast cancer and completed surgery (lumpectomy) and radiation therapy in November of that same year. She now considers herself to be in "good" health.

May is a 46 year old nurse who lives in Prince Edward Island. She and her husband, a farmer, have three young children, ages 9, 13, and 16, who are currently living at home. May was diagnosed with cancer in October of 1994 and underwent surgery (lumpectomy) and radiation therapy. She completed her round of treatment in December of 1994. Currently, she considers her health to be "good".

Marla, a 37 year old woman from Quebec, was living in Prince Edward Island at the time of the interview as a result of her civil service employment. Marla has recently been relocated to British Colombia. She is divorced and her current partner is also a full-time employee in civil service. Marla was living alone at the time and does not have any children. She was diagnosed with cancer in January of 1995 and underwent surgery (mastectomy) and chemotherapy. She completed her treatment regime in July of 1995. Marla describes her current overall health as "excellent".

Finally, Elizabeth is a 40 year old rural Prince Edward Island woman who is currently not working due to illness. She and her husband, who works full-time, have 5 children (aged 18, 17, 14, 8, and 6) of which 4 live at home. Elizabeth was

diagnosed in October of 1995 and underwent surgery (mastectomy), chemotherapy, and a bone marrow transplant. She completed treatment in April of 1996. Elizabeth reports that her overall health is "excellent".

Overview of Thematic Synthesis

A reconstructed view of sexuality is presented through the issues that the women deem important. The participants provided a broader view of sexuality than the current literature as their sexual meanings went beyond the act of intercourse and sexual desire. The women rarely spoke about areas such as intercourse and orgasms. They described deepened relationships with family and friends, emphasis on intimacy and connection with partners, friends, and family, a zest for life, integration of new body image, and the influence of everyday life, such as work and child care on their sense of selves as women and their sense of sexuality. This reconstructed view of sexuality is evidenced by the common themes the women shared during the interview process. The thematic synthesis of the experience of sexuality and the reconstructed sexual self-image for breast cancer survivors is presented in Figure 1 (p.56).

Figure 1 represents the context, challenges, and changes to women's sexuality after breast cancer. The outermost circle in this figure depicts the thematic cluster of "Personal/Social Constructions of Sexuality". It is this theme that represents the context by exploring a woman's prior constructions of sexuality that she held before she was diagnosed with breast cancer. This theme characterizes the messages about sexuality that a woman has received during her childhood through her adulthood from her family, peers, and social institutions. The messages from these external forces have been internalized to create each woman's sense of herself

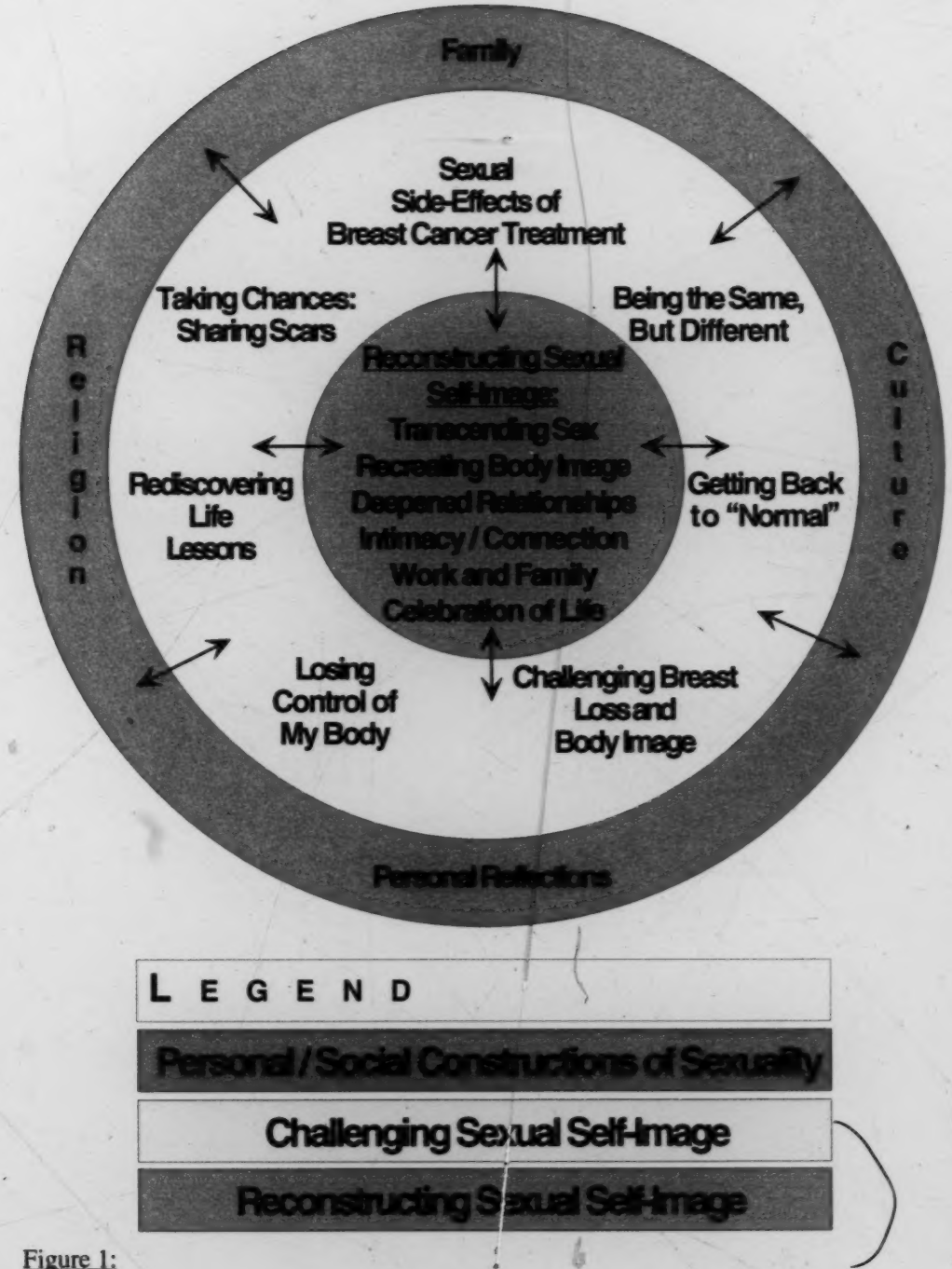

Figure 1:

Sexuality for Breast Cancer Survivors: Reconstructing Sexual Self Image

and her sexuality (Daniluk, 1998). An example of a message that a participant received which helped form her personal constructions of sexuality follows:

> The emphasis in our house...was on study, being a good student. It was never on appearances being important. Certainly not with my mom or dad. I had an aunt who felt that dressing up and you know looking beautiful was very important in order to catch a male...but that was never a message in my mother's home.

Moving inward in Figure 1, is the second theme "Challenging Sexual Self-Image" which represents the experience of breast cancer and the many challenges that present themselves to a woman's sense of self and sexual self-image when she is faced with this illness. Some of these challenges include the removal or partial removal of her breast; sexual side-effects of chemotherapy, such as vaginal dryness (Schover et al., 1995), and probable infertility (Kaplan, 1994); and sharing her scars with significant people in her life. To exemplify the challenge inherent in this theme, one participant reported:

> In terms of radiation, I mean I felt like a piece of meat. It looked like a piece of meat...There were days when I wondered if it was ever going to heal, I mean that you could do that much damage to a breast...it was so sore and raw.

The innermost circle in Figure 1 depicts "Reconstructing Sexual Self-Image". The experience of breast cancer challenges a woman to make sense of the breast cancer and her sexual self-image, thereby creating a new sexual identity. The participants created new meaning out of the changes in their bodies and sense of selves and integrated this with their experiences of themselves, their experiences with breast cancer, their past experiences of sexuality, and then integrated these into new sexual self-images. As a result, the women provided an expansive view of sexuality. For example, one participant describes her new sense of sexuality as follows:

> To me, it's a celebration of being alive. I've come to that definition now,

particularly since I got cancer of course. Like, it's amplified that very much...It's not just intercourse. It's feeling alive and it's feeling sensations and your body being the tool between you and the world of the physical.

Although the colors in the figure differentiate the thematic groupings from one another, the arrows represent the fluidity of these thematic groupings. For example, women's personal constructions of sexuality will likely influence the experience of breast cancer and the challenges that they face as a result of the cancer diagnosis and treatment. That is, a woman's identity may be profoundly influenced by the removal of her breast if she holds prior beliefs that her breasts are an important part of her sexuality and her sense of self. Furthermore, the removal of her breasts may challenge her to recreate and reconstruct a new sexual self-image.

To summarize, the following themes were identified as indicators of women's experiences with breast cancer and sexuality.

Personal/Social Constructions of Sexuality

- Family
- Culture
- Religion
- Personal reflections and experiences

Challenging Sexual Self-Image

- Losing control of my body
- Sexual side-effects of breast cancer
- Challenging breast loss and body image
- Taking chances: Sharing scars
- Elements of healing
- Getting back to "normal"
- Being the same, but different
- Rediscovering life lessons

Reconstructing Sexual Self-Image

- Transcending sex
- Recreating body image
- Deepened relationships
- Intimacy/Connection
- Work and Family
- Celebration of life

Description of Themes

Personal/Social Construction of Sexuality

Women are bombarded with messages about sexuality from parents, siblings, friends, school, television, movies, religious institutions, and many other mediums. These messages can have a profound impact on their sense of selves and on their personal views of sexuality. If women receive messages about breasts and sexuality that have a profound impact, how do these messages play themselves out in women's adult years, when suddenly they are faced with a disease that has the possibility of altering the appearance of their breasts. The women interviewed spoke of messages they received from family, religion, culture, and their own personal reflections. As a result, women's stories were placed in the context of their lives. Also, it is important to note that although these messages are divided into categories, these messages tend to overlap into other clusters as well. For example, messages that participants received from their culture may also be reinforced and shared by their family of origin. As a result, these categories are not mutually exclusive as descriptions from the participants often fit into a number of different themes.

Cultural messages.

Some women interviewed mentioned that their cultural heritage had some

kind of influence on their sexuality. In addition, cultural messages also included societal messages conveyed through television and other mediums. One participant, Jane, believes that her cultural background inhibited any discussion about sexuality.

> Well, my background is British, which probably accounts to some degree to the fact that you did not discuss sex or sexuality, or even bodily functions, I was going to say in polite company, but even, you know, within the home.

Marg also views her cultural and religious background as influential to her sexuality as a young girl.

> I was raised by an Irish Catholic mother which tells you 99% of the atmosphere that I was raised in. I'm the only girl of a very dogmatic Irish Catholic mother...So I was raised in an atmosphere where sexuality was very suppressed, absolutely.

Beth expressed similar views of her cultural background and educational training.

> I grew up in a sort of straight laced European family. There wasn't a whole lot of talk about sexuality. I think that there was very little done in school, certainly nothing about it.

May believes that generational differences exist. She believes that sex is spoken of more freely today than during her adolescence.

> It's sort of a different era when I was growing up because number one, it wasn't a word (sex) that was mentioned like it is everywhere you turn, every t.v. you turn on, every radio, everything...Whereas when I was growing up it wasn't there.

Barbara Anne perceives that she received the "wrong" messages from society; that is, physical appearances are valued.

> (I received) all the wrong kind of messages...I grew up too fast...First I was short and dumpy and then all of a sudden I grew straight up, and then began to fill out quite a bit...But I found even in those days that there's a lot in relation

to how you appear to people...that even your parents weren't aware of.

Religious messages.

Participants also mentioned that religion had influenced their sexual development. As stated above, Marg believed her "Irish Catholic mother" created an oppressive atmosphere when discussing sexuality. Jane felt that her religious background influenced her decisions on how to express herself sexually and caused her to question the church's beliefs about sexuality.

> Being sort of raised with that dilemma, the decision that I might have sex outside of marriage, was almost a matter for the confessional...There becomes so many guilt associations with sex, and I don't think sex should ever be associated with guilt...And having been raised to always question beliefs and censorship and all of those kinds of things, that caused me to pause, to sort of question, and I thought, "No, no, no, no, that is your opinion. I don't think God said that".

Familial messages.

The participants discussed varying messages about sexuality that they received from their parents, siblings, and extended family. The women recall messages about sexual activity, physical appearance, and traditional women's roles. Jane addressed messages she received from her mother about the joylessness of sex, privacy of sexuality, sexual virtuosity, and even perhaps how her mother's childhood experiences may have influenced her own sexuality.

> Sex was never quite nice. It was almost an obligation. I can't remember my mother ever speaking of the joy in a partnership...They (i.e. parents) were always very private. And that was fine. I never thought that I was shut out, and probably this same privacy has sort of expanded to our family...I think mothers in those days always extol their daughters to be virtuous...And there were loose women who were always referred to and if a girl became pregnant

> and was not married, she wasn't exactly drummed out on the street, but certainly her character was called into question...I think that's because your mother is sort of fairly rigid in her expectations of having a good girl, and all the connotations of the, I don't know, fifties and sixties, of what the good girls were.

Beth discussed that her mother made an effort to talk about sexuality while she was growing up and she received strong messages that academics were valued more than physical appearances. Although appearances were not valued in her home, Beth received messages from extended family members that stressed the importance of appearances and importance of traditional women's roles.

> I think my mom, I do remember my mom trying sort of to try to explain, trying to explain, things to me before I started menstruating, and I think she did in terms of the frogs and the birds and the bees, and I had a hard time making the connection...The emphasis in our house, in our home, was on study, being a good student. It was never on appearances being important. Certainly not with my mom or dad. I had an aunt who felt the dressing up and you know looking beautiful was very important in order to catch a male, that kind of message. But, that was never a message in my mother's home, in the home with my parents...I used to visit with her and my cousins...and she was very concerned, her big concern was that they should get married...And she felt looks was part of what was important for a woman, and good looks meant being slim and attractive to the opposite sex, and dressing well, and you needed that in order to catch a man.

Barbara Anne shares how her parents' separation was influential in her personal development. She also discussed how she as a woman connected to her mother as a woman and how she consequently related the abused part of her mother with being a woman.

> Partly because I think, my parents separated at a very early age, at my very early age...and I was the only kid on the street that had divorced or separated parents...and while you might perceive something to be right, you can't always follow that right, because you don't, you might not have the strength of your convictions, or it hasn't been established well in your roots...The sense of where I was feeling, well, if your mother is abused and you relate well to your mother, you loose the self-worth of being a woman.

Marla's family expressed to her that sexuality is a powerful, natural occurrence. She recalls subtle messages about body shyness and believes that the 1970's were influential in overcoming this body shyness.

> It's loving, sexuality. It's more than just the act here. I didn't get that many messages through my family. Mainly that it was a natural event...natural aspect that you have to have knowledge...and it's very powerful...my mom said it was a really powerful thing...And then the expression of your sexuality, well what you did with the person was up to you. Love...he loves you back. It' s an exchange of very deep caring and loving. That's the message I got...Although there were some subtle messages of shyness about your body. I think that's pretty typical for women. Mom was raised by nuns...and so although she was , she is a proud woman, and she always looks after herself, and looks the best she can and dresses really well, there's still a certain shyness about her own body...(Re: passing on shyness to her) For a little bit, but I grew out if it (laughs). Yeah, I grew out of it because, well, I'm 37, so, I grew up in the '70's. So you know, things kind of opened up (laughs).

Personal reflections.

The women who had participated in this research had all done a great deal of reflecting back upon their own experiences and described how they examined and integrated the messages they received and how the messages have shaped their

understanding of sexuality. Some women believe that their breasts are very important to their sense of self while others believe that their breasts are not crucial to their personal development. Beth discussed that her breasts were not a focal point in her personal development . She speculates that breast cancer may have had a more significant impact if her breasts held more personal meaning to her than they did. She also attributes this lessened impact of breast cancer to the messages she received from her mother.

> So I never particularly focused on my breasts, or making them look wonderful, or anything like that, they were there, they were part of me. I certainly wore swimsuits and didn't worry about it terribly. I mean, I would have liked to have been a little slimmer, I was always a little chubby, but there was not a huge concern about that....I don't know how I would have felt if my breast had been terribly important to my appearance and I'd always put a big stock on that. I think what really made the difference (i.e., in the importance of breasts) were the messages that I got from home...the overwhelming message, certainly from my mother, was that what was important was that I be the best I can be, that I study. I think it must have been useful. I was not concerned about how I was going to look, that was not my immediate concern.

Marg believes that breasts set her apart from men and that breasts are symbols of women's sexuality.

> I think all women or most women in our culture, our breasts are what make us different. You know, our breasts are very much of what makes us female. And if I really stop and think about it, is I have never thought about my vagina at all. The first thing to me, that was part of me being a woman, was not my vagina, it was the fact that I grew breasts, and that was what made me different from my brothers.

Barbara Anne explains that certain experiences that occurred while she was growing up demanded that she learn about sexuality at an early age.

> My life, people wonder how I ever survived it. I was sexually abused at age eight and that definitely had...nothing was important for many years...Life itself didn't have the meaning that it should have had. If you're sexually abused at eight, at age eight, you know more about the sexual aspect of life than many who are 25...(Abuse impacted entering adulthood and relationships) very, very, badly. That's where you have the lack of self-worth, therefore, you have to build that up you see, which I did. It didn't come easy.

Elizabeth tells how she is more open with her children than her parents were with her and as a result, her children are comfortable discussing sexuality. In addition, she recounts that sexual intercourse was not an important aspect of her personal and sexual development.

> It's different for me and my kids. We've been talking about it since they were little. So, it's not something they're even uncomfortable with...The sexual act to me has never been all that, just never been all that important, I guess. I guess because when I was a teenager at the time that everybody was probably thinking about it, we just weren't. You know, our friends were like brothers and sisters and there was nothing sexual about them. My breast isn't who I am. It's part, it was a part of me, but it wasn't that important a part

Challenging Sexual Self-Image

At the time of their cancer diagnosis, the eight participants were very different; that is, they all had their own distinct experiences, unique personalities, and varying views of sexuality. Given this, it is quite remarkable that they shared some common ground in their experience of breast cancer and the impact of cancer on their sexuality. Breast cancer presented the women with many challenges to their sense of selves as women and their sense of sexuality. These challenges manifested

themselves in biological and physical form; such as, feeling a loss of control, experiencing sexual side-effects, experiencing the difficulty of breast loss and changes in body image, and sharing surgical scars with other people. Challenges to a woman's sexual self also had psychosocial aspects; such as, the importance of resuming their sex lives which provided a sense of normalcy, rediscovering life lessons that helped the women make sense of the disease, and healing that occurred that supported the integration of these challenges into a reconstructed sexual self-image.

Losing control of her body.

Women saw their body as a known quantity; that is, something that they were able to know about and understand. Thus, breast cancer became a challenge to the known. Some women spoke of the disappointment and anger with the realization that the cancer occurred beyond their control and that their bodies did not warn them of the disease. This loss of control challenged their sexual self-image as some women felt let down by their bodies. As a result, resuming sexual activity became a way of restoring a sense of control. Perhaps feeling like the cancer occurred without warning causes some women to be very vigilant with new twinges and pains in their breast and chest area. Some women, like Marg, voiced their concern that they are particularly sensitive to sensations in their breasts and that sex is sometimes disrupted so they can check to make sure that there are no new lumps or unfamiliar breast sensations.

> You lie there and you think about, I can remember thinking, "How could I have not known. Why didn't I feel it. Why didn't my body tell me something" and "If it didn't, then is it happening again and I don't know it? And where is it happening?" to the point where you get yourself into a frenzy and you're ruled by fear and you're terrified of the unknown.

Jane also said she felt betrayed by her body and resuming a normal sex life was

important to regain some control.

> And did I feel let down by it (i.e., cancer)? Yeah, you bet I did. I felt angry at my body, and that this had localized in my breast...So it was important to resume that part of our lives. When everything else is out of control, you can control so little. It's a new normal day, struck everyday, and here is something normal, you know that you can bring to the next part of your life and it was important.

Beth echoed this feeling that her body was out of control.

> The sense that I really didn't have any control over my body, which I felt that I had had up to then was a big shock...There's always the fear that it might recur.

For many women like Lynn, the feeling that cancer had occurred without warning provokes a sense of vigilance with new aches and pains.

> When we're having sex, I do think about it. It doesn't occupy my mind, but you know, if something hurts a little, you kind of go, "hmmm". You know, is something there? But we kind of tease about it, too, because I say to him, "Okay, just check here". Because I do still have scar tissue, and so we still check and you know, it's kind of like "just check this out".

Sexual side-effects of breast cancer.

The participants discussed many other side-effects of breast cancer that can impact sexuality besides the loss of a breast. Some women acknowledged that the chemotherapy treatments had lessened their sex drive, contributed to nausea and fatigue, and in some cases, had caused premature menopause. Other women discussed that a loss in sexual pleasure, weight gain, and depression were side-effects of chemotherapy that challenged their sexual identity. Any of these side-effects alone could interfere with their sexual relationships with their partners and women's perception of their sexual selves. The effects of radiation therapy left some women

feeling "like a piece of meat" which certainly affected their sexual desire. The pain of the radiation burns caused some women to be cautious to any physical touch.

Lynn describes how the emotional struggles she experienced impacted her sexually. Now she recognizes depression to be a natural reaction to cancer but was not prepared at the time for how the depression would impact her sexuality. For Lynn, the onset of premature menopause and the side-effects of tamoxifen greatly influenced her sexuality and added to the difficulty of coping with cancer.

> In terms of the radiation, I mean I felt like a piece of meat. It looked like a piece of meat...There were days when I wondered if it was ever going to heal, I mean that you could do that much damage to a breast...it was so sore and raw. The other thing that I guess I went through and I believe that quite a few women go through...is the emotional turmoil...it probably had to do with cancer, but I think it had to do with just my emotional well being and all of the medication that they put in and what it does in terms of depression. And dealing with that, which I think has an impact to in terms of your sexuality and your sense of well being...And I guess for women to know that sometimes this is a pretty natural part of the process...But I think the other part that comes into it is the whole issue with menopause and what happens in menopause. And I think that's what's playing more havoc with me right now is the weight gain from the tamoxifen and the dryness...I think that's gonna play more havoc with my sexual identity then all this stuff before...Then you're dealing with hot flashes and that's not romantic...So, you're kind of dealing with cancer and menopause.

For Elizabeth, the onset of premature menopause which contributed to painful intercourse and lessened sexual desire presented many challenges to the sexual functioning aspect of her sexuality.

> Now sexually, our life has changed. I went through menopause, so there was

problems with physical problems, having sexual intercourse, dryness and things like that. Plus a lot of mood changes so it's difficult for me to feel sexual...Actually, there is a lack of desire, you know. So I kind of have to, not necessarily fantasize, but I kind of have to build myself up to it. And you have to plan it a little more I guess, because it takes a little longer to feel sexual. I don't think it has anything to do with my body, I think it has to do with the chemicals...The only thing that affects my libido is the fact that I'm tired, I go to bed very early at night and the desire is low because of the hormone thing.

Marla discloses that she was unprepared for the numbness she experienced in her breast and chest area after surgery. This loss of feeling and consequent loss of sexual pleasure was very alarming. For her, there was a determination and desire to regain sensual pleasure that was temporarily lost.

Because what I realized afterwards when the scar was healed and you know, a few weeks, was that first of all I had no feeling on the scar itself, the skin was numb, and under the arm where they took the nodes, no sensation. Nobody had told me about that and that was a really big shock. That was a big shock. And that was the biggest sense of loss, was the sense that I had lost a potential for sexual pleasure, because I had felt so much in my breast and it was gone. That was--not to feel, to me, that was devastating...I thought it as a challenge to gain back, my first thoughts were "I have to gain back the feeling. I have to get back the pleasure I had". I didn't want to lose that, you know...It creates a few problems physically. Chemo did make me a little dryer and it creates, you know, I did have some lesions now and then, had to be careful, stay clean and it had these logistic problems, and that's how I saw them.

Challenging breast loss and body image.

The participants had a great deal to share when discussing challenges to their

body image and sexual self-image that they faced when they lost a breast or part of a breast. Certainly, many women felt a self-consciousness with respect to the changes in their body's appearance and described their bodies as mutilated or disfigured. Some participants discussed the need to create a new self-image which would correspond to their "new" body image. Another central theme was the function of the prosthesis. For example, one participant expressed that women are the "masters of disguise" and undoubtedly this theme of concealing any breast loss was quite evident during the interviews. As a result of the body-consciousness that is an inherent part of the breast cancer for many, some of the women discussed that the prosthesis increased their own comfort level. There was comfort in appearing the same to other people after the surgery. The prosthesis served an important function as it "buys time" to accept the physical changes in their bodies. Jane speaks about the breast loss:

> They (i.e., surgeons) are going to take a breast. Well, that's pretty significant. So was this going to make a great difference of how I felt about myself? "No", because I could hide it. If they had taken an arm or a leg, that would be much harder to hide. Women, I think, are sort of masters of disguise, you know. We use make-up and we hide the black shadows, and we enlarge our eyes with mascara...we sort of squeeze into things, and so we become the masters of disguise...And so was that going to bother me on the outside? "No". Was that going to hurt me on the inside? "Yes". Except that I have a partner who says, "But you're so much more than a boob"...In actuality, physically seeing it gone...yes, it's a daily reminder, you know, cancer is always, you've been there, it's never going to go away, and every time you step out of the shower, there is this reminder.

Similarly, Beth discusses her body-consciousness and the use of the prosthesis to "buy time". Also, she describes the process she experienced from wearing the

prosthesis to questioning the actual use and function of the prosthesis.

> I remember that horrible feeling that a part of me was going to be lopped off, that I was going to be maimed and I was very fearful of that...To look just as you had looked before and that would be a great comfort...so there's that comfort that you will go out there and face the world the same. You do need time to get used to the fact that you aren't the same physically...So the prosthesis was a comfort in those terms...that it bought me time.

For Lynn, she wonders if she would have felt differently about her body if she had a mastectomy instead of a lumpectomy.

> Now for me that is fairly easy because in terms of the surgery that I had, it isn't as drastic as it is for some who have had mastectomies...I think it would have affected me more if I'd had major scarring or I had not had a breast, because like I say, for me there's not a lot of difference...Well, it (i.e., mastectomy) may have just taken me a little bit longer to accept, and to feel good about me sexually...If we'd had a period of time, you know, while I was healing and that kind of thing where nothing was happening (i.e., sex), I think I could very easily have fallen into, "I'm less than whole".

Marg's body-consciousness was confounded with the role of dating and feeling undesirable by possible dates.

> Cellulite-- it's much easier to turn your back, it's pretty hard to conceal a missing breast. So I was very conscious of it...Certainly, early in the relationship, I was very conscious and constantly tried to cover the missing breast as it were...When I left my marriage, I honestly did not ever think I would have another relationship. And certainly that I only had one breast was another factor in that thinking, absolutely no question. Who would want a woman with one breast when there's so many good looking, bright women with two breasts, right. Why would somebody want somebody with one

breast?

For May, who had a lumpectomy, she wanted a prosthesis to mask the appearance of the disproportionate breasts.

> I still do have two (i.e., breasts), but I just don't have them the same size. When I get dressed to go out, nobody can tell because I have a prosthesis. Before (i.e., the prosthesis) I felt very uncomfortable and that's why I didn't go...'Cause they're different, it's quite noticeable, you know. It's quite noticeable--the difference in the size. And the thing is, if I had to have mine off, I would have them off because the need is there and I would and it wouldn't bother me, but I won't take them off until the need is there...because they're part of you.

Elizabeth is also aware that the prosthesis enables her to appear similar to everyone so she can enjoy the comfort of anonymity. She is also aware that her children model her beliefs so she demonstrates that breasts are not a defining feature of being a woman.

> My breast isn't who I am. It's part, it was a part of me, but it wasn't that important a part. I had already had my children, and nursed my children and not that I didn't need it anymore...If I made a big deal out of it, I didn't want to freak out my children. And I didn't want my teenagers to think that, you know, I have a 16 year old and she doesn't need to think that breasts make her a woman. Any my sons don't need to think that that's what they should be looking for in women...Well, your prosthesis is good for a lot of reasons. For your self-esteem, you know, just so that you look a little more like everyone else, because believe it or not, it's 1997 but people stare and do stupid, say stupid things...it's nice to be anonymous and walk through the hall and or go somewhere and not feel like you have cancer.

Taking chances: Sharing scars.

Most of the women discussed the difficulty of showing their scars to significant people in their lives, most notably, their partners. Scars presented a challenge to the presentation aspect of sexuality. Showing their scars to other people in the women's lives allowed them to "test" their new self-image. There were feelings of fear when exposing their new scar and their partners' reactions were important in buffering against their self- and body-consciousness. Beth explains that she was fearful that her husband would not find her attractive. She also describes her growing comfort of being naked in a gym changing room with strangers.

> I remember the fear that my husband would not find me attractive...that it would effect our relationship, that he would be repelled by the scar and the fact that I just had one breast...So each new situation, even dressing and undressing in front of my grandchildren...how was I going to tell them about it, and that took some working through that kind of thing. So different time frames...I think with my grandkids and changing in front of them in the changing room when we're going swimming, it was just too awkward. It was ridiculous, and I thought, this is nonsense. This is me and I'm going to have to find a way to explain it to them in a way that's not frightening to them. And so on, so often sort of covering up and doing all kinds of gyrations a couple of times, I thought, this is nonsense. I'm not going to do that.

Marg also relates how her partner's honest reaction to her mastectomy was important to their developing relationship.

> And I said to (new partner), "Well, do you know what that (i.e., mastectomy) looks like?" And he said, "No". And then proceeded to tell me, "If you're waiting for me to say that it's okay, I don't know because I don't know what it looks like". So, I said, "Well, it looks pretty weird, when I take off my bra, I take off my breast and so it is kind of weird looking". And when we

> progressively got to the bedroom, and I got my bra off, he looked at me and he said, "You're right. That's pretty weird looking" (laughs). And it was exactly what he should have said.

Marla explains that her partner's feedback was important to her sense of her beauty.

> And of course I'd ask my boyfriend and he'd say, "Yeah, it's (i.e., remaining breast) as female as anything", and you know, he'd say, "I'd love to touch it", you know, even if there's only one, there's a whole one there. I should say that was very important because that's part of your feedback.

Getting back to "normal".

For many of the women, it was important to resume a "normal sex life" with their partners. Resuming sexual activity confirmed that they were indeed alive and willing participants in life. Cancer was not going to negatively impact their relationships and expressing their sexuality provided a sense of normalcy. In one sense, sexual activity became a tool to normalize their live. Jane discusses the importance, for her, in resuming sexual relations.

> It was very important to make love after my surgery. It was life affirming. It was in defiance of disease, if you like. It's like falling off a horse, you've just gotta get back and do it...I don't know, you think, okay, because a healthy sex life has been important.

For Lynn, sexual intimacy with her husband affirmed that the disease would not impact her sense of self.

> My husband was wonderful there, too, because we were having sex when I still had a drainage tube in you know, which was great because then I felt that wasn't my identity, you know, this wasn't going to negatively effect who I was.

Marla discusses the importance of expressing her sexuality throughout the treatment. Sexuality was life affirming at a time when life was at it's most precarious.

> It (i.e., sex) was very actually, very important for me during the chemo. I was very active through the chemo. I don't know if everybody is but it was one of the moments when I would forget about everything else and feel good. Yeah, I would definitely feel more alive. At that time, it was life affirming. Now, I lost energy though, and I couldn't, I got tired towards the last few months and we, the rhythm slowed down a bit and I couldn't keep up by times. But it was never a negative experience, he was always so understanding. It was a very positive, bright moment in my weeks and days...I enjoyed it. Yes, it's a celebration of life to me. So, I think maybe that's why it was all the more important that it continues through the treatment. You know, that's what made me feel normal in life.

Being the same, but different.

Many of the participants struggled with whether a cancer diagnosis had changed their sense of self or sexuality. Initially, many of the participants sought affirmation from others that they were the same person that they were before the surgery, and before they lost a breast. Some women felt "incomplete" with one breast, while one woman who was not in a relationship felt undesirable by men. However, in time, these women came to a place where they did not feel different or incomplete, but instead, felt the same as before and that the essence of who they are had remained the same. Beth describes important messages and affirmations that she is the same person as she was before she was diagnosed with cancer and how this aided in her process of realizing that the cancer did not influence her sexuality.

> I remember a letter that I got from the mother of a friend of mine when I had been diagnosed with breast cancer and she wrote to me and said, "Remember you are still the same person with or without your breast, you're still the same lively person" and that had a tremendous impact on me. That was a very important letter that I got and it changed my thinking, as well as the

> relationship that was resumed after the surgery with my husband. So that I certainly feel that now I feel that it's quite irrelevant to my sexuality or to the kind of person I am or to relationships I have...Yeah, it's totally irrelevant (i.e., having one breast), the fact that I have one breast, or I don't have one breast. I think it really is, totally irrelevant to me now, in terms of myself.

Lynn also discusses messages she received.

> Just that kind of feedback, that I'm still the same person that I was...For women, our physical bodies are tied up in that sense of that I'm okay, and that my body's okay, and my husband still loves me is very important, if it didn't involve sex at all. But just that kind of feedback. That I'm still the same person that I was.

Marg disclosed earlier: "Who would want a woman with one breast, when there's so many good looking, bright women with two breasts, right?". With time, she, too, came to realize that she is still a gifted woman with a great deal to offer.

> It didn't change the way I felt about myself as a woman, I certainly still felt like I was a complete female...(Message she gives to students) Here I am you guys, you respect me, and you respect my knowledge, and you value my opinion, and I only have one breast and I'm still as much of a woman as your mother and your grandmother, and your aunts and I'm still your teacher and a damn good one at that.

Rediscovering life lessons.

All of the participants attested to the fact that breast cancer has been a life-changing experience. The experience has changed who they are as women, has changed the importance of their lives, and it has provided many opportunities to examine their lives and make significant changes to enhance their lives. Also, some women are enjoying many different aspects of their sexuality more; for instance, greater pleasure in sexual activity and increased intimacy with their partners. Breast

cancer has enabled some women to have a deeper understanding of the importance of self-care and the importance of staying healthy and feeling good about themselves. In general, many women seem to have developed a stronger self-image of themselves. Beth discusses how cancer reaffirmed the importance of celebrating life.

> Celebrating life, just feeling so pleased that I was alive and well. I felt it was a badge of courage, more than anything else...I've been through an experience that, you know, has given me a new sense of the importance of life, of celebrating life, that kind of thing. So, it's changed that way, I think, of how fleeting life is. And special moments. Enjoying every moment, and feeling really blessed at where I am right now, but other than that, I think it's heightened that kind of awareness...I think it's changed me as a person. It's changed me in the sense that I value everyday that I have that's healthy.

In Marg's life, cancer was an opportunity to examine her life and an impetus to make significant changes accordingly.

> I guess there's really nothing in your life that doesn't change with the experience of cancer. And I'm not sure if that's just related to breast cancer or if it isn't the whole cancer thing. It impacts every single element in your life. It changed my relationship with my kids. It changed my relationship with my husband. It changed my relationship with my friends, with my family, with my mother, with my brothers, anybody, everybody, it's impacted...Maybe it was an impetus that I'd been looking for, maybe I was looking for something to get me out of the whole marriage thing, the whole situation and that was a graceful way of doing it.

Since her cancer diagnosis and treatment, Barbara Anne has enjoyed a new appreciation for her spouse, a recognition of the importance of life, and the importance of fully living life.

> He probably treated me more tenderly. He was always afraid that he'd hurt

me, which showed a kindness that I'd probably hadn't experienced with him previous...life isn't quite as long term as we might have thought, therefore, we should cherish what we have now. In other words, know that you're still alive and vibrant, and that you can do things that you did previously.

For Marla, cancer provided an opportunity to explore and expand her sexuality. She has a greater desire to live and has tapped into a new sense of mind-body connection.

I feel more like a woman than I did...And you just explore. I just went and explored more. And there was the aspect that more than ever, I felt this life force in me. This life affirming energy more than ever...so I had more of that than ever, a desire to live more than ever. Translate into being more of a woman than ever...When I went through chemo, in order to get through that without too much problems, I felt like I had to pay a lot of attention to my body, and actually ever since I got sick, it's one thing I do now, I never did it, it reconnected my head with my body and, like, my feelings. And I had to pay attention to what the body said, "Okay, I'm too tired, I'm going to lay down". You know, which I never did before. I always put myself last, I always looked after everybody else first, right? And you always ignored your own messages and your own body's messages. Well, through this you have no choice. In order to handle the chemo and not be too sick or whatever, I realized that I had to listen, to keep myself calm, rested, happy...So what happens then when you get better, you have this new awareness that doesn't go away...It was too precious...It enhanced a lot...And now, it's (i.e., sexuality), yes, it's still a big part of my life, of course. It's enhanced, it's better, it's bigger. It's still me. One part of my body is gone, but I gained a whole lot more.

Reconstructing Sexual Self-Image

The women in this research were challenged by the experience of breast

cancer to recr[illegible]e and reconstruct their sexual selves. Breast cancer presented many challenges to the participants' sexual self-image as a result of sexual side-effects of treatment, breast loss and body image, and sharing surgical scars with important people in their lives. As a result of these experiences, the women have recreated their sexual self-images.

Women's sexual self-images by nature are complex, dynamic, and ever-changing. The women in this research described many elements of their sexuality that they felt had been recreated or reconstructed as a result of their experiences with breast cancer. Although these elements are interconnected and interrelated, it is important to delineate the structure in order to develop a deeper understanding of how the participants' have reconstructed their sexual self-images. These elements need to be seen as a whole in order to truly reflect their interconnectedness.

Transcending sex.

Many of the women described how their sense of selves as women, and their sense of their sexuality, went beyond the act of sex itself. Being sexually active is one small part of women's sexuality. It is interesting to note that this is an area that women may have been cognizant of before their breast cancer diagnosis, yet, the cancer diagnosis may have heightened their awareness. That is, before cancer, women may have been aware that for them, sexuality was more than the act of intercourse, but since their diagnosis, this is an area of which they have garnered a new found awareness. For example, with Lynn, sexuality is more involved than intercourse and includes more than performance aspects of sexuality.

> I think for me, it's more than the actual intercourse. It's the intimacy around that, and at times there was no intercourse, and kind of that sense of being a sensual being and a sexual being, you know.

Marla expressed similar thoughts about the role of sex in her sexuality since her diagnosis and treatment. The removal of her breast challenged how she viewed her

sexuality and the role of intercourse in expressing her sexuality.

> It's not just intercourse. It's feeling alive and it's feeling sensations and your body being the tool between you and world of the physical...I realize that sexuality is from within anyway. It comes from within. If you have it, your energy inside, then it will come...it will come out of your pores. So, it doesn't matter if you have one (breast), two, or three or none.

Recreating body image.

Women who have had a lumpectomy or mastectomy often have the challenge of incorporating their "new" body image with their body image before the breast surgery. For many women, recreating a new body image was a lengthy and difficult process. Through their breasts, women often provide loved ones with nurturance and nutrition, and are often a source of comfort and pleasure for themselves. The loss of a breast which has been an important part of a woman's life can be very challenging. Although each woman discussed their struggles with body image, one participant in particular, Marla, richly illustrated this process in which she struggled to bridge the "old" body to the "new".

Marla's mastectomy proved to be a tremendous challenge to her preconceived images of "sexy". She described her fear that she would lose sexual pleasure since her breasts had always been a source of sensual delight. Marla's new body-image of a one breasted woman was neither in accord to what she felt was sexy, nor to what society construed as "sexy". Her internal messages which were constructed from societal messages did not correspond to her new body. As a result, Marla took on a challenge. She started the process of creating new, strong, sexual self-images to correspond with her new body-image. First, Marla describes her relationship with her body, in particular her relationship with her breasts.

> When that became obvious we had to do that (i.e., mastectomy), there is a part inside me, for a brief time, I thought, "This is it, my sexual life is over".

> Because my breasts were always very, very important...in my sexuality. I don't know about other women, but I've always felt a lot through my breast...it was always a very important part. I was proud of them, you know. It was one of my, as far as being a woman, it's the one aspect I was most proud of...You know, I didn't like my thighs, I didn't like my hips too wide and all this stuff, but my breast...It was a part I was happy with. I feel a lot through them. Through touching and caressing and what not...I felt a lot, and to me that was, to lose that (was difficult).

Marla continues to discuss the impact of the breast surgery on her body image. Marla recognizes that she had internalized the sociocultural messages about women's bodies and sexuality; that is, that perfectly shaped and rounded breasts are a necessary part of women's sexuality. Subsequently, Marla's newly changed post-mastectomy body presented her with an immense challenge.

> Now before the operation I didn't realize how much I was losing. All I could think about was the image of course. And I thought briefly, "Well, that's it. I'm not going to feel turned on anymore. I won't feel these urges anymore". Because I think a part of feeling good sexually about yourself, like you have to feel good about yourself and about your body. And by doing that, by taking the breast, all of a sudden you have this body that doesn't correspond to any images of...any sexy images. Because everything you see on television, in magazines you see two breasts...you see cleavage...you see the form, right. And it's in your mind, and as a sexual person you get turned on or whatever, you have these images in your head, or I do anyway. And that's conditioned into you and you have no control over that, I mean it's there since I don't know what age. And you start to register, and so all of a sudden, you know, you're asymmetrical. You have one, only one. It just doesn't make sense, it doesn't correspond to any internal messages...about sexy internal

> messages...appealing, attractive, whatever. And so I thought, "I'm never going to feel turned on again"...For the first period, I couldn't, if I saw on television, breasts were just too obvious because they're so present...even in sitcoms, family shows...it's just they're played up all the time and I couldn't, I would close my eyes, turn my head away, just I had a really hard time seeing that and not cry.

As a result of these internalized messages about the importance of two breasts, and Marla's changed body, she focused on creating new sexual self-images that, for Marla, would inspired strength and beauty.

> I took it as a challenge and--okay, I have to find new images. I have to put images in my head. I have to rebuild as far as myself, self-image is concerned. And one that came to me was the image of an amazon. The legend of the amazon woman, and I think a lot of the ladies think of that. The lady warrior, either they take, they cut their breast off themselves, or they lose it in battle, or whatever. And I saw myself as a warrior at the time. And that was a symbol of life and strength and so that was a good positive image... The other thing I remember the first few weeks when I got back home and I was looking at my chest, and it looked like a young boy's...a little boy's chest, you know. So flat and so I thought, "Well, that doesn't really look ugly, it just looks like a little boy's chest". Or, it reminded me of a little ballerina's...I always loved ballet actually, and it just reminded me because they don't have breasts, very big breasts. So, I thought, "Well, if I ever had to lose the other one, that would be the picture that I would have in my mind"...Something beautiful and positive.

However, although she had a new symbol of strength and beauty, she still needed to integrate this new body image into a new sexual self-image.

> But still, like even with the image of the amazon warrior, what not, it was still,

it was still a struggle to put that in your mind, and feel sexual about it. It was not sexual, it was life affirming, but it was not sexual yet. Like in the beginning if I started to feel aroused I would get these images in my head of me with two and all of a sudden, "Wow", gone, feelings gone. Can't feel anything. Cannot, cannot enjoy this anymore. Like the image would just stop everything, kill the mood. You know I would see two breasts and then the mood killed because all of a sudden I don't have two. This is not me. It's not true to me. It's a lie. And so I did go through a lot of stages. Now the stage I'm at, the stage I'm at now is two and a half years since the surgery and now the image comes with one (i.e., breast) and that's no problem. I still feel aroused and it doesn't turn me off. It's acceptable and it's sexy in it's own way. Well, I think it was trying to replace the images and I think really the warrior was one...I think was a very important step about feeling good about your body and how you look.

Deepened relationships.

For many women, living through and beyond a potential life-threatening disease, such as cancer, allowed them to develop a fuller appreciation for people in their lives and their relationships. The tenuousness of life made itself shown and women worked at making changes in their lives which often reflected a desire to enjoy those close to them. To illustrate this, Lynn described the deepening of her relationship with her partner.

If anything, it helped me to re-evaluate how I spent my time, and it brought us closer together because of what I went through...I had increased time because I wasn't working, so we had time to work on the relationship...So, I made changes in my life in terms of my job, and in terms of the commitment and the number of hours. So that I think has probably contributed in terms of a more positive sexual relationship. I would say, I mean in terms of the experience, I

would say since the having cancer, we have sex more frequently. I find it more enjoyable...Probably, it's more important to me to have a sexual relationship and a healthy sexual relationship with my husband now than it was before. Because I think what cancer does is it helps you appreciated what you have for family, and you know, my whole thing is, is that you know, if this comes back down the road, will I have lived in-between?...In many cases, it's that how lucky we were to have gone through this, and to have learned this lesson in our lives.

Similarly, Elizabeth has experienced stronger relationships with friends and family.

If anything, I feel not more sexual, more close and more intimate with my family because of what happened. So, I don't feel further away. And actually, I feel a lot healthier sexually than some people that haven't been through what I went through. I can feel an intimacy with a girlfriend...but it almost feels like that intimacy to me, my intimacy is heightened because of having had cancer. And I know that life is short and I know that I have to soak my children in, and soak my family in, and soak my friends in, in case something does happen

Intimacy and connection.

When describing the role of intimacy and personal connection in women's sexuality, many women acknowledge the importance of intimacy between people. Many women in this study held the notion of intimacy at the pinnacle of their sexual self-images. Intimacy is an important and vital concept in the expression of love for another person. To depict this idea, Jane described the importance of intimacy in her partnership and how her sense of intimacy has changed over the years due to challenges such as breast cancer and ageing.

To me, friendship is just such a component of how you sort of feel...But there is a sharing and a warmth that I think...there are depths that you reach when

> you are both totally relaxed and just focused on each other...It's in those moments that you can share perhaps your deepest thoughts, maybe your hopes, your fears, because there is such security in that isolated moment...The comfort of just holding hands and just being held and comforted and a closeness there that is very healing and that, too, is part of the ageing process, you know, like your sexual urges change. They moderate as you age. You tend to build partnerships in different ways, and you come to terms with this because even if the spirit is willing, the flesh is sometimes not quite so co-operative...That you can share the very worst of yourself and the very best of yourself and not be judged. It's really quite incredible.

Marg also believes that intimacy plays a crucial role in her sense of sexuality. For her, intimacy and connection are often portrayed as subtle expressions of her sexuality.

> A lot of sexuality is...when you're grocery shopping and he puts his hand on your shoulder or takes you by the back of the neck, or something. To me, those are very sexual, and they're very subtle, as opposed to overt sexual moves. For me, that is a really major part of my sexuality and my response to his sexuality...I guess there's no question, you know, that whole love, whatever that love thing is, is at the very fundamental roots of it. It's caring about somebody, and feeling the freedom to express yourself sexually and to accept his sexuality.

Work and family.

For most women, work and family can impact their sexual self-images. As mentioned previously, many aspects of women's sexual selves are closely entwined. When external pressures from work, family, and child care surface, women may find it more difficult to express and connect to their sense of selves and sexual self-images. Many women feel pulled in different directions and lack the energy and

focus to participate in important relationships. Women's lives become even more complicated when faced with a life-threatening illness such as cancer. To illustrate this, Lynn described how her sexual self is connected with her everyday life happenings, such as work and child care.

> And I can tell you (laughs) from experience that as a workaholic, I didn't have much of a sex life in my job. Because I basically worked, and when I wasn't working I was mothering, and there wasn't a lot left for the relationship with my husband. And thank goodness he was patient, to wait around until I finally got time. Sexuality has as much to do with what's happening in your life. And just the ability to be able to relax, and to enjoy and not to have your head full of work and other issues...I'd been putting off things, so I think that's all tied up with your identity in terms of who you are and what you can do...And I think, you know, sexuality fits in there as well.

Celebration of life.

After conquering and surviving breast cancer, women feel more fully engaged in their lives and may experience their sexual selves more fully and completely. Sexuality is celebrated as an important aspect of living well. For many women, expressing sexuality is a beautiful and natural part of their personhood. For Marla, sexuality is an expression and celebration of life that can be derived from natural and raw elements of life, such as enjoying nature.

> Sexuality to me is very beautiful and natural expression of who you are...I feel it in the way I move, in the way the air moves around me...I feel it right through. I feel it all the way to my fingertips. My whole body...I'm very much aware of my whole body and how it feels...and how everything feels around it. So, it to me, sexuality is a lot of sense, sensations...and feelings...how you take in the world to your body, you know...I see it as a broad definition. Sexuality is a very broad definition to me. It's, I mean you

get pleasure out of things. That part of, to me, that's part of your sexuality. Like enjoying the hot sun on your skin. Or a nice hot bath...and enjoying the smells of the garden. It all makes you feel alive. So, to me, sexuality is a kind of raw energy from feeling alive...and feeling good. That's, it kind of ties into that...And then when you get more specific, you know, in terms of being sexual with somebody, to me that is one of the greatest expressions of being alive and feeling happy...to be there...To me, it's a celebration of being alive. I've come to that definition now, particularly since I got cancer of course. Like, it's amplified that very much...

Summary

Although each participant experiences her sense of sexuality and her breast cancer diagnosis and treatment in her own way, they shared some common ground as well. Each of the women discussed their personal constructions of sexuality before their cancer diagnosis and the role that family/culture/ religion/personal reflection played in the development of their sexuality. Despite their unique backgrounds and sense of sexuality, these women have some shared experiences of breast cancer that challenged their sexual self-image. The women discussed feeling that they were losing control of their bodies, they recounted the sexual side-effects of breast cancer and its treatment, they spoke of the challenges they faced with regards to their body image and breast loss, they described different elements of healing they encountered, and they explained the risks they took by sharing their scars with loved ones.

These themes that speak to the experience of sexuality for breast cancer survivors, coupled with their personal constructions of sexuality, indicate that sexuality is a complex phenomenon not easily described. The women in this research describe a spirit of sexuality that is complex, rich, and diverse. The language in which these participants explore and discuss sexuality does not fit descriptions found

in standard literature about breast cancer and sexuality. For instance, many woman expressed that sexual intercourse was only one small aspect of their sexuality, whereas the majority of literature on breast cancer and sexuality focuses on this aspect. Instead, these women offer a new, reconstructed paradigm of the impact of breast cancer on sexuality. This reconstructed view of sexuality will be discussed in the next chapter.

CHAPTER FIVE

DISCUSSION

When I speak of the erotic, I speak of it as an assertion of the lifeforce of women; of that creative energy empowered, the knowledge and use of which we are now reclaiming in our language, our history, our dancing, our loving, our work, our lives.

-Audre Lorde

Women's experiences and descriptions of sexuality after breast cancer are far more complex and include much more than intercourse and sexual desire, that is, women's sexuality is more than biology. A woman's sexuality is comprised of her feelings for her body, her feelings for herself, and her feelings for those around her (Kitzinger, 1985). However, the breast cancer literature does not contain such descriptions of sexuality. This quantitative literature addresses such concerns as frequency of intercourse after cancer treatment, ratings of painful intercourse, and ratings of sexual desire. Although these are important aspects of women's sexuality, they do not adequately address women's concerns or experiences with sexuality after breast cancer.

Women in this study reveal what is important in their individual sense of self and sexuality since their diagnosis of breast cancer and provide an increased understanding of how breast cancer can impact their sense of selves and their sexuality. In particular, this chapter includes the findings from the three thematic clusters (Personal/Social Constructions of Sexuality, Challenging Sexual Self-Image, and Reconstructing Sexual Self-Image) and are compared and contrasted to the current literature on breast cancer and sexuality. This chapter also contains an exploration of particularly unique perspectives on sexuality as described by the

participants which often went beyond the sexual functioning aspects of sexuality found in the current literature. Finally, this chapter will conclude with a discussion on limitations to and implications for this particular research, and possible suggestions for future research.

Personal/Social Constructions of Sexuality

The women in this study experienced and reported many similar aspects of sexuality. The purpose of the open-ended interviews was to allow the women to discuss issues that were central to their own personal experiences of sexuality. Each woman described messages that they received which shaped their understanding of their sexuality. These messages arose from interpersonal relationships with family and friends, media influences such as television, film, and print, and social institutions such as religious, government, and educational institutions (Bruess & Greenberg, 1986). Sexuality, indeed, has a cultural base. For example, young girls playing with "Barbie" interact with a doll who has unattainable body proportions. Adolescent girls and women are bombarded with magazine covers of unhealthy, waif-like models. These common examples send young girls and women unhealthy messages about the type of body to which one must aspire. Similarly, some religious institutions have been outspoken advocates against masturbation, homosexuality, abortion, being unmarried and cohabiting or "living in sin", and divorce, and instead present the "virgin Mary" as the role model for modern women. However, some religious institutions have become more willing to accept sexuality as an essential aspect of humanity, to recognize that all persons are sexual beings, and that sexual pleasure is a healthy goal with either a same-sex or opposite-sex partner (Bruess & Greenberg, 1986).

Women's sense of who they are as sexual beings can be understood after they examine and make sense of messages and learnings they have encountered during

their lives. This concept has also been described as the "Person-Environment Interaction" (Daniluk, 1998, p.13). In this interaction, women examine their external environments to make sense of their internal experiences. For example, women create their personal sexual meanings in part by examining the messages from their external worlds. For example, many women receive messages about the importance of physical beauty instead of the importance of confidence, excelling academically, or building relationships. However, not all of these messages imparted from family or society are integrated into women's sexual constructions. Daniluk explains that there are several factors which influences the integration or elimination of these messages into personal constructions. These factors include the "persistence of the messages, her investment in the opinions and beliefs of the messenger, her values, the source of the messages, her age and life stage, and her current sexual self-construction" (Daniluk, 1998, p.14). The incorporation of messages is a complex interaction that is dependent on many factors.

In this research, all of the women discussed previous messages they received about sexuality. How these women make sense of, or construct, their sexuality is shaped by many external and internal factors. For example, family of origin, religious institutions, societal messages, and the media influenced how these eight women make sense of themselves and their sense of sexuality. These external influences also combine with women's own personal experiences with sexuality and personal reflections of sexuality to produce a unique sexual self-image. Andersen and Cyranowski (1994) refer to this as "sexual self-schema" in which thought patterns about women's sexual selves are "derived from past experiences, manifest in current experience, influential in the processing of sexually relevant social information, and they guide sexual behavior" (p.1079).

Daniluk (1998) explains that women's "interpretations of the way their bodies, desires, and actions are defined and valued within their culture necessarily shape their

experience and understanding of their sexuality" (p.13). She continues to write:

> Women are continually bombarded with messages from significant others (e.g., parents, friends, lovers) and from the culture at large (media, schools, medical professionals, etc.) regarding their sexual needs and natures. But as indicated earlier, sexual meanings are co-constructions. They are individually created by women based on their unique histories, life circumstances, and particular contexts (Daniluk, 1998, p. 13).

When women's prior constructions of sexuality are coupled with the experience of being diagnosed with a life threatening disease, women's sexuality may become an even more complex phenomenon which is more complicated than present research would suggest.

Women's sexuality is certainly a complex phenomenon. Each women has her own unique relationship to her body and the pleasure and meaning she derives from her body may depend on the many messages she has received and internalized about sexuality and body image from personal, familial, and cultural experiences. As a result, when diagnosed with breast cancer, each woman experiences some common issues in her own way. For example, many of the women discussed the process of accepting their changed body after their lumpectomy or mastectomy. However, this process was different for each woman depending on their previous constructions about the importance of their breasts. Accepting their altered body was perhaps not as painful for these women who had not placed significant importance on their breasts and the appearance of their breasts. Yet, for those women who had taken great pleasure in both their breasts, they had a more difficult time accepting the breast loss.

Despite these differences in upbringing and socialization, it is quite remarkable that the participants indeed do share common experiences with regards to breast cancer. These themes, such as feeling a loss of control, sexual side-effects of breast cancer, sharing scars, and rediscovering life lessons, coupled with previous

constructions of sexuality make for a complex definition and experience of sexuality. The participants provided a detailed description of their sexuality and what their sexuality means to them as women and breast cancer survivors. By doing so, they support an expanded view of sexuality similar to that of Kitzinger (1985) and Daniluk (1998). This view challenges notions of sexuality as a narrow, intercourse based view of sexuality, to a more full-bodied, full person sexuality that encompasses the entire context of women's lives and relationships.

Challenging Sexual Self-Image

When discussing the impact breast cancer had on their sexuality, the participants described many experiences that challenged their sexual self-image. For example, sexual side-effects of breast cancer, body image concerns, sharing scars, and losing control of their bodies were some experiences that the women encountered which enabled them to recreate their sexual identities. The women described common experiences which may not only impact sexual functioning, but also each woman's sense of self and her sexuality. These experiences are presented below and are related to the relevant research literature.

Losing Control of Her Body

Many of the participants spoke of the disappointment and anger they experienced when they realized that the disease occurred beyond their control. In a recent study, 45% of 195 breast cancer patients indicated that they felt a loss of control over their bodies, their health, their social activities, and their future which they attributed to their cancer diagnosis (Lowery et al., 1993). For some women in this current research, it was important to resume their sexual lives to regain a sense of control. For these women, sexual interaction became a gauge in which to measure the amount of control they were regaining. Other women became very vigilant of new aches and pains as they worried that the cancer would resurface without warning.

The literature refers widely to the fear of recurrence and uncertain futures as a frequently documented concern of cancer survivors (Cella & Lesko, 1988; Gorsynski & Holland, 1979; Northouse, 1981; Pelusi, 1997; Schmale, Morrow, & Schmitt, 1983). Also, other researchers have reported that if a woman frequently worries about undetected cancer cells, sexual activity can be impacted as she may become overattentive to her bodily sensations (Dobkin & Bradley, 1991). As a result, breast cancer survivors can experience sexual activity to be a great source of anxiety.

Sexual Side-Effects of Breast Cancer Treatment

The women in this research study discussed many side-effects of breast cancer treatment that impacted their sexual self-image. For these women, chemotherapy was particularly detrimental to their sense of sexuality. Chemotherapy produced serious side-effects such as fatigue, nausea, and depression that interfered with their sex drives and sexual relationships with their partners. In a study of postmastectomy women, the occurrence of depression stemmed from the changed sexual relationship between the woman who had a mastectomy and her partner. For example, 25% of those women reported that their partners no longer saw them naked and this caused feelings of dissatisfaction with themselves and their relationships (Morse & Furst, 1982). It is important to also realize that some women do not experience a loss of self-esteem, feelings of unattractiveness, loss of sexual response or pleasure following mastectomy. This certainly challenges any assumptions that mastectomy automatically results in psychosocial difficulties (Reinisch, 1990).

In addition to the above short-term side-effects, chemotherapy can also produce a premature menopause which can also effect sexual desire, orgasm, and cause vaginal dryness and painful intercourse. These findings are supported by previous research which has shown that women treated with chemotherapy were 5.7 times more likely to report vaginal dryness, 3.0 times more likely to report decreased libido, and 7.1 times more likely to report difficulty achieving orgasm (Young-

McCaughan, 1996). Additional research has shown that women who had received chemotherapy had significantly poorer body image, had sex less frequently, had more vaginal dryness and dyspareunia than women who did not have chemotherapy (Schover, 1994). Chemotherapy certainly presents women with many challenges to their sense of sexuality and sexual self-image.

Challenging Breast Loss and Body Image

A mastectomy or lumpectomy presents numerous challenges to a woman's body image and sexual self-image. Most women in this research were quite aware of the changes in their bodies' appearance and some women described their bodies as "mutilated" or "disfigured". For many, with the loss of the breast came a changed body and the challenge for a new body image. When changes occur to a woman's body as a result of childbirth, menopause, or a mastectomy, she has to build a new self-concept of self-identity and sexuality based upon her new physical and mental image of herself (Maldonado, 1995). Similarly, a woman who has had a mastectomy or lumpectomy needs to reinterpret her role as a sexual woman and redefine her identity by accepting her new body image (Boyd, 1984).

The effects that a mastectomy may have on a woman's body image may be symbolic of the importance that society places on women's breasts as symbols of womanliness, femininity, and sexual attractiveness (Hopwood & Maguire, 1988; Margolis et al., 1989; Mock, 1993). Mock (1993) contends that the loss of a body part that is significantly related to feminine identity "results in a negative alteration in body image and self-concept" (p.154). Furthermore, the degree of negative alteration can be expected to be related with the degree of physical change and with the *meaning* of the body part to the person involved. Maldonado (1995) asserts that the societal attitude that equates a woman's femininity exclusively with her breasts is an outdated one, and one which arises from a male world view that implies a woman's breasts are crucial to attracting men. This patriarchal view further asserts that nothing

is more important to a woman than attracting a man. Maldonado explains that if a woman accepts the role that society has created for her, and if she has been conditioned since childhood to measure her worth by her external beauty, the loss of her breast can threaten every fundamental component of her identity, that is, her femininity, her self-image, and her measure of herself as a person. However, women have created the opportunity to re-examine and challenge their role in society and create a new concept of womanhood that is better suited to their lives than the lives of their mothers and grandmothers.

The loss of a breast and an altered body image presented challenges to these women's sexuality as some felt less sexually desirable to their partners. This breast loss and negative body image presented unique stressors to the one woman in this research who was not in an intimate relationship following her breast cancer treatment. One participant in this current research questioned what she had to offer potential dates since she had lost a breast to cancer. In support of these findings, previous researchers have reported that one main concern for unpartnered women was their fear that they would be unable to obtain a long-term committed relationship on account of their illness. Some women expected that men would find them less appealing than women with two breasts. In addition, the women themselves viewed themselves as less sexually desirable and they expected that they would be rejected on account of their illness (Gluhoski, Siegel & Gorey, 1997)

Some women took the challenge of losing a breast as a chance to influence others around them. Participants were aware that their children or grandchildren would model their beliefs and attitudes, and as a result, they wanted to demonstrate that breasts were not a defining feature of being women. Similarly, in a study which examined the "lived experience of surviving breast cancer", eight women were interviewed to explore their experience of cancer. Women in this study described the influence that they had on others related to their cancer experience. These women

acknowledged that they had influence on those close to them since friends and family seemed to be taking cues from the women as to how to respond to them. These participants seemed to agree that cancer was a family disease as it impacts all involved (Pelusi, 1997).

Taking Chances: Sharing Scars

The participants discussed the difficulty of showing their surgical scars to significant people in their lives, most notably, their partners. As mentioned earlier, the experience of mastectomy and lumpectomy often results in a changed body and a challenge for a new body image. This new body image often necessitates a new sexual self-image. For many women, showing their surgical scars to other people represents an opportunity to test out their new self concept and self-image of themselves.

Many women fear rejection and fear that they will not be found attractive when exposing their scar to people close to them. This finding is supported by a recent study of 223 breast cancer survivors. Fifty-five percent of the women reported that their breast cancer scars were displeasing to them since their breast surgery and they were uncomfortable being seen in revealing clothes such as night-gowns and bathing suits (Polinsky, 1994). In an additional study of 50 breast cancer survivors an average 6 months post treatment, only 33.3% of patients who had undergone a mastectomy without reconstruction indicated that they had appeared nude in front of their partners (Wellisch et al., 1989).

Getting Back to "Normal"

For some breast cancer survivors, it was important to resume sexual activity and a "normal sex life" with their partners before and after treatment. For some women, sexual activity seemed to be a support, and for others, it was a tool to normalize their lives. Resuming sexual activity was life affirming and provided a sense of normalcy to an unfamiliar situation. Also, being sexually active allayed

some women's fears that breast cancer would interfere and change their sexual relationships with their partners.

Although participants described the importance of resuming sexual activity, this area is not addressed in the breast cancer and sexuality literature. Readings and literature searches did not reveal previous studies or narratives of other breast cancer survivors expressing the importance of resuming sexual activities. Other questionnaires have asked whether women have engaged in sexual activity since breast cancer, but have not attempted to address the meaning of resuming this sexual activity. However, in one related reading exploring grief and sexuality, Kitzinger expresses that women may feel "almost driven to sex" (p.283). In addition, sex "in the face of grief can be a striving for reassurance, a determined affirmation of life when confronted by death or loss" (Kitzinger, 1985, p. 284). As for the lack of literature in this area, perhaps this area is overlooked; however, most of the participants in this current research expressed that sexual activity was an important part in their treatment and recovery.

Rediscovering Life Lessons

For the women in this research, the diagnosis of breast cancer has been a life-changing experience. In particular, the challenges to their sexual self-image has changed their self-concept. The experience of cancer has changed how they see themselves as women, and it has changed how they view the importance of their lives. Consequently, they have given themselves permission to put themselves first, thereby enriching their lives. These women are also enjoying many aspects of their sexuality and often have increased intimacy with their partners. For some women, cancer has reaffirmed the importance of celebrating life and appreciating friends and family. For others, cancer provided an opportunity to explore and expand their sexuality. Some women have tapped into a new sense of mind-body connection which has enhanced their lives and their sense of being women.

Similar to this current research, there have been a number of recent articles which attest to the fact that breast cancer survivors have experienced positive life changes (Carpenter, 1997; Ganz et al., 1996; Pelusi, 1997; Polinsky, 1994; Zemore, Rinholm, Shepel, & Richards, 1989). Content analysis of 87 interviews with women who had undergone mastectomy revealed that 64% of the respondents indicated that having had breast cancer made a difference in their family life; more specifically, that the partners and children had become closer and more caring, their partners and children had become more helpful, and that the breast cancer survivors have a more positive outlook on life (Zemore et al., 1989). Similar results were reported on a sample of 223 breast cancer survivors in which 74% of the sample expressed that they felt the breast cancer experience had changed their life for the better (Polinsky, 1994).

Like the women in this current research who managed to find the positive in a very difficult situation, so did the women in a research study by Ganz and her colleagues (1996). Ganz examined the psychosocial concerns and quality of life of breast cancer survivors at 2 and 3 years after their cancer treatment. Most of the women in the Ganz study came away from the breast cancer experience with a positive and optimistic outlook. Their cancer experiences enlightened them in that they found their lives to be richer in many ways. For example, the participants reported that their relationships with friends and family improved and deepened, one-third of the women reported that their sexual relationships improved, and many women reported improved self-image, and feeling more self-assured having survived the cancer experience. Again, the concept of a changing sexual self-image is evident in the literature.

The results of a recent phenomenological research study on the "lived experience of surviving breast cancer" were also consistent with this current research (Pelusi, 1997). In Pelusi's research, eight women were asked to describe their experience of breast cancer. One of the themes identified was "self-transcendence"

which is described as "a characteristic of developmental maturity whereby there is an expansion of self-boundaries and an orientation toward broadened life perspectives and purposes" (Reed, 1991, p. 64). The participants in this present research saw self-transcendence as a significant component of their cancer experience. The women reviewed who they were in life before their cancer experience, who they were after their diagnosis and treatment, and what they found now to be meaningful in their lives, and how they prioritized their life activities and life work. The participants mentioned that their life priorities were changed, that their lives had new meaning in relation to their cancer experience, and that all the participants reviewed their lives and explored who they are currently and who they want to be in the future.

Reconstructing Sexual Self-Image

Creating Meaning

Kegan (1982) proposes that the most fundamental thing people do is make sense out of what is happening to them in their lives. People have a strong desire to "create, shape, and form meaning in our sense of ourselves and our lives" (Daniluk, 1998, p.9). This is also true of sexuality. Women have strong needs to create meaning in their sense of selves as women, and accordingly, "the creation of sexual meanings is of fundamental importance in any woman's experience of her sexuality and perception of herself as a sexual person" (Daniluk, 1998, p.9). As mentioned earlier, sexual meanings are developed and created based on the external messages a woman receives, personal experiences she encounters, and the internalization of these messages and experiences into her sexual self-image. When an experience such as a life-threatening illness occurs, her basic assumptions about who she is as a woman and her sexual-self may be shattered. Consequently, women's sexual meanings and sexual identities may not be a static occurrence, but instead, may be a fluid phenomenon.

Daniluk (1998) suggests that "as a woman lives with the physical changes of puberty, menstruation, and menopause, or undergoes events such as hysterectomy or sexual violence, the meaning she ascribes to these experience will be based on her psychological development, her values, and the beliefs she has come to hold about herself as a sexual person" (p.11). These events, including breast cancer, may require women to recreate their sexual meanings and sexual self-images. Changes to a woman's body, for example, a mastectomy, need to be integrated into a woman's view of herself as a sexual person and her sexual self-image (Daniluk, 1998). The women in this current research were challenged in many ways to create meaning from their breast cancer experience. Breast loss, sharing scars, sexual side-effects of treatment presented challenges to women's sense of selves and sexual self-images. Facing a surgically altered body, experiencing premature menopause, and feeling that one is losing control of her body may present overwhelming challenges to her basic assumptions about who she is as a woman and her sexual-self. Consequently, she is challenged to make sense of this and recreate her sexual self-images.

Recreating Sexual Self-Images: New Understandings

The women who participated in this research integrated the experience of breast cancer into their views of themselves as women and their sexual self-images. These women created sexual meanings that are quite different from performance-based definitions of sexuality in the breast cancer and sexuality literature. In this present research, sexuality was a diverse and rich phenomenon. Expressing and experiencing women's sexuality was believed to be much more involved than the act of intercourse. There were many common themes shared by most, if not all, of the women in this study. Each women reported that sexuality transcends the act of intercourse; that is, sexuality is more than "having sex". Indeed, sexual interaction is but one piece of the sexuality puzzle. In addition, each woman described how their lives had been enriched and their relationships with family and friends had been

strengthened and that these changes had enhanced their sense of selves as women. For example, one woman said, "It (i.e., cancer) brought us closer together...it's more important to me to have a sexual relationship and a healthy sexual relationship with my husband...it helps you appreciate what you have for family".

An interesting element for many women in recreating their sexual self-image is rectifying the dissonance they often feel between their body image before cancer and their body image after cancer. Breasts mean many different things to many different women. Some women take great personal and sexual pleasure in their breasts while others do not attach specific meaning or importance to their breasts. As a result, the alteration or removal of women's breasts may be a very unique and personal experience for women. Integrating the "old" body image into a new and healthy body image may be difficult and challenging for some women. For example, one participant in this research, Marla, described the disharmony she felt when she was sexually intimate with her partner after her mastectomy. She reported that when she and her partner were in the initial stages of being intimate, she would close her eyes and picture herself with two breasts. This was an image that would often shock her into realizing that she no longer had two breasts.

As a result of the dissonance between the actual body she would see in the mirror and her perceived body image she would hold in her mind, she needed to find a way to bring the two images together. She focused on recreating a new sexual self-image that would inspire strength and beauty. The image of amazon women and small breasted ballerinas came to mind. These images enabled Marla to begin accepting that her "new" body which was different from her "old" body was still a body worthy of love and admiration. These images helped bridge the gap until she was able to integrate the internal sexual self-images with her actual physical appearance and appreciate the strength and beauty of her one breasted body.

Recreating Women's Sexuality: New Understandings

The participants described aspects of sexuality which are not replicated nor described in the current literature on breast cancer and sexuality. In current breast cancer literature one finds performance-based language such as "intercourse", "frequency of intercourse", "desire for intercourse", and "ability to achieve orgasm". It is clear from the participants' descriptions of sexuality that a re-languaging and reconstruction has taken place. These women use terms such as "friendship", "intimacy", "more than actual intercourse", "natural expression of who you are", "sexuality has much to do with what's happening in your life", and "sense, sensations, and feelings". Although previous researchers have focused on important aspects of sexuality, there appears to be somewhat of a discrepancy in what researchers are studying with regards to breast cancer and sexuality and what women describe as important aspects of their sexuality. The participants' descriptions of their experiences are different than what are portrayed in the current breast cancer and sexuality literature. Instead, using women's own language, this research explored women's own definitions and experiences of breast cancer and its impact on their sense of sexuality.

Although the personal descriptions of sexuality in this research are incongruous with breast cancer literature, they are consistent with conceptions of sexuality found in some women's sexuality literature. Drawing from interviews about women's own experiences, Kitzinger (1985) describes sexuality as more than biologic and as involving the entire context of women's lives, relationships, and emotions. She states that "the evidence from women is that sexual feeling depends to a large extent on other things that are happening to us and our feelings about our own identity and how we value ourselves" (p.10). Certainly, the breast cancer survivors in this research agree with Kitzinger's position. Women in this research believed that there is a normal ebb and flow of sexual intimacy in any relationship, and as such,

sexuality may be impacted by daily activities such as work and child care. As sexuality involves all aspects of women's lives, it is easy to examine how women's daily lives can impact their sense of sexuality. Women juggle many different roles. The lives of breast cancer survivors in this study were busy with work responsibility, child care responsibility, personal and family life responsibilities, and as a result many of the women felt pulled in different directions. Breast cancer diagnoses added a whole new dimension to their hectic lives, adding difficult treatment, side-effects, and recovery. Feeling stretched did not provide much of an opportunity to reconnect with a woman's personal sense of sexuality nor did it provide an opportunity to express this sense of sexuality. As one participant reported:

> Because I basically worked, and when I wasn't working I was mothering, and there wasn't a lot left for the relationship with my husband...Sexuality has so much to do with what's happening in your life. And just the ability to be able to relax, and to enjoy and not to have your head full of work and other issues...so I think that's all tied up with your identity in terms of who you are and what you can do...sexuality fits in there as well. (Lynn)

Many women have been socialized to trust and to maintain traditional views of their sexuality. As a result, women may have a twofold perception about sexuality, as what they have been taught may conflict from what they actually experience. Hence, women were taught the societal stereotype of what it means to be a woman and to be sexual (i.e., intercourse with a man), but their own experience is notably broader. Women's sexuality as defined by women is a diffuse, total body experience, not just the act of coitus (Bernhard & Dan, 1986; Kitzinger, 1985). Women in this study described sexuality in a similar fashion:

> It's in you all the time when you act, when you move...it's part of you...feeling female...I feel it in the way I move, in the way the air moves around me...I feel it right through. I feel it all the way to my fingertips. My whole body...I'm

very much aware of my whole body and how it feels...and how everything feels around it. (Marla)

Given that women may experience their whole bodies to be sexual and that sexuality involves the entire context of women's lives and relationships, it is easy to imagine how the occurrence and treatment of breast cancer could impact women's sense of sexuality. Indeed, breast cancer influences much of a woman's life and many of her relationships such as with her partner, family, friends, and co-workers. Women in this research study reported that they had a difficult time showing their scars to sexual partners, the side-effects of chemotherapy impacted their sexuality, the loss of a breast or changes in a breast presented challenges to women's body image, and at times, they felt that as if their bodies had betrayed them. If, as Kitzinger asserts, women's sexual feelings depend on other things that are happening to them is true, then the impact that a life-threatening disease, such as breast cancer, can have on their sense of selves as women and their sense of sexuality is immense and complicating. A diagnosis of a life-threatening disease is certainly traumatic and can confound all aspects of a woman's life, relationships, and sexuality. However, it also provides women with an opportunity to reconnect with their sense of selves as women and their sexuality and to recreate their sexual selves into strong, full-bodied, exciting, sexual self-images.

Summary of Reconstructing Sexual Self-Image

Prior to the diagnosis of breast cancer, the participants in this research had unique, personal, sexual self-images. These sexual self-images were created from past and present experiences and learnings about sexuality, and integrated into their understanding of themselves as women and their sense of sexuality. When the women were diagnosed with breast cancer, they needed to incorporate this new experience into their sexual self-images. They faced many challenges to their

sexuality, such as the affects of breast surgery on their body image and sense of sexuality, and the side-effects of breast cancer treatment, such as chemotherapy and premature menopause. In essence, the women created meaning out of the changes in their bodies and sense of selves and integrated this with their previous understanding of their sexuality. These new meanings, then, were based on their experiences of themselves, their experiences with breast cancer, their past experiences of sexuality, and then integrated into new sexual self-images. This notion of a reconstructed sexual self-image is not well-addressed in the breast cancer and sexuality literature. The participants provided a broader view of sexuality than the current literature as their sexual meanings went beyond the act of intercourse and sexual desire. They described deepened relationships with family and friends, emphasis on intimacy and connection with partners, friends, and family, a zest for life, integration of new body image, and the influence of everyday life, such as work and child care on their sense of selves as women and their sense of sexuality.

Unique Aspects of Sexuality

When describing how breast cancer can impact sexuality for women, it's important to remember that with breast cancer comes unique challenges to women's sexuality that other women may not encounter. Most women do not fear that they have lost control of their bodies to a life-threatening disease. The side-effects of chemotherapy and premature menopause also cause changes to women's hormones and sexual functioning that may occur only to breast cancer survivors. Losing a breast or part of a breast also presents complex challenges to women's body image that may not be present in those women who have not met the misfortune of breast cancer. However, breast cancer also affords women the unique opportunity to deepen their appreciation for many aspects of their lives, such as family, friends, relationships. Breast cancer survivors, such as these eight participants, have often

explained that their lives have been enriched and their significant relationships have become more intimate and satisfying.

The women who participated in this research described their sexuality in terms which often went beyond any scholarly definitions and which often challenged traditional, performance-based definitions of sexuality. There was an interesting parallel between nature and sexuality by a participant in this research and a sexuality writer. Kitzinger (1985), in her book Women's Experience of Sex, explains that sexuality "can infuse the whole of life. It includes things like the excitement and sense of physical well-being that comes from walking in the country when autumn leaves are falling in the crisp air, gold and scarlet and rust" (p.10). Similarly, in this present research, Marla expresses that "You get pleasure out of things...That's part of sexuality. Like enjoying the hot sun on your skin. Or a nice hot bath...and enjoying the smells of the garden. It all makes you feel so alive".

To further illustrate that the participants used language which reconstructs sexuality into a more woman-centered sexuality, the following quotations are taken from the interview transcripts in which women are describing their sense of sexuality. The participants described sexuality in unique ways such as "a lot of sexuality to me is the. .sort of affectionate touches...when you're grocery shopping and he puts his hand on your shoulder", and "...sexuality is a kind of raw energy from feeling alive...and feeling good...it's feeling sensations and your body being the tool between you and the world of the physical...sexuality is from within...it will come out of your pores".

Limitations of the Research

In addition to discussing the findings of this present research, it is also important to discuss the limitations of this study. A qualitative methodology lends itself to the inherent possibility of researcher bias. The interpretation of the

interviews and the thematic analysis may be influenced by the researcher's presuppositions and biases. Through the process of self-reflection, and putting any presuppositions in written form, the researcher can be aware of such biases and attempt to minimize any influences that these may bring to the research results. In addition, the process of self-reflection can also allow the readers to be cognizant of the researcher's bias and predispositions (Colaizzi, 1978; Osborne, 1990; Valle & King, 1978).

The validity of research studies are often strengthened through methods of triangulation. For example, data triangulation, investigator triangulation, theory triangulation, and methodological triangulation are four available methods for strengthening the validity of research studies. The results of this current research may be restricted and less generalizable because of the limited use of these triangulating methods. Only single sources of information were available in this study. That is, only the participants themselves were interviewed as the research did not approach family members or friends of the participants to gain a number of different perspectives. Similarly, the sole method of collecting data was in the form of the research interview. It may have been helpful to combine different, multiple methodological perspectives to obtain a better, more substantive picture of the women's realities. Additionally, there was only one researcher as this research did not employ the use of several different researchers or evaluators. However, this research was supervised and the data analysis was shared with colleagues and the participants themselves for the expressed purpose of providing validity for the results. In addition, this results of this research were also triangulated with the breast cancer and sexuality literature that was reviewed by the researcher.

As mentioned previously, the criterion specified that potential participants were free of metastatic disease. However, one participant, Elizabeth, reported that she had received a bone marrow transplant which was probably indicative of

metastatic diagnosis. However, Elizabeth indicated that she did fit the criteria, considered herself to be of good health, and was eager to participate in the research. As a result, the researcher decided to include Elizabeth in the study. Although Elizabeth's bone marrow treatment may be seen as a limitation to the research as this treatment does not fit the criterion of the study, it is believed that Elizabeth adds more depth and breadth to the sample and supports the validity of the research as she shared in many of the common experiences of the other participants. Indeed, Elizabeth, with her poorer diagnosis and subsequent treatment, shares in many of the common themes of sexuality and breast cancer as the other seven participants.

Due to the limited sample and unique characteristics of the women in this research study, the themes may not be generalizable to all breast cancer survivors. Age of the women, stage of disease, type of treatment and surgery, and prior constructions about sexuality, may contribute in their own way to the experiences of the participants and to the experiences of other breast cancer survivors. However, because qualitative research is not concerned with statistical generalizability, this research is considered generalizable to the extent that it resonates with other breast cancer survivors and they agree with the outcome of the research. Thus, if the thematic analysis resonates with the experience of other women, it is said to have empathic generalizability (Osborne, 1990).

Similarly, not all women who have had or will have breast cancer have the same level of education, socio-economic status, and sexual orientation as the eight women who participated in this research. It is not known whether women with lower levels of education, different socio-economic status, and different sexual orientations will experience breast cancer and sexuality in the same manner as these women. As a result, this may also be considered a limitation to this research.

Directions for Future Research

As this research is one of only a few research studies on breast cancer that examines different elements of sexuality other than performance-based components of sexuality, it may be useful to encourage others to continue this exploration. Previous researchers have stated that women's sexuality needs to be redefined based on women's own experiences, and not of the experiences of those researchers who develop questionnaire tools (Bernhard & Dan, 1986; Daniluk, 1993; Gilligan, 1992; Miller, 1986). As a result of asking women to describe their own experiences with breast cancer and its impact on their sexuality, women expand upon and deepen the understanding of women's experience from their perspective, thus becoming an integral part in redefining sexuality.

All eight of the participants in this present research describe themselves as heterosexual women. Although these women describe elements of sexuality that do not include male-female intercourse, it may be interesting to conduct this research with lesbian and bisexual women to gain further perspective and knowledge with sexuality and breast cancer issues. For example, when examining personal constructions of sexuality, lesbian women may have had unique experiences and may have been given different messages about sexuality. Society, religious institutions, and families often imply that there is one correct definition of sexuality, that is heterosexuality, and anything else is deviant and/or immoral. It would be interesting to examine how the prejudicial messages lesbians receive from others may influence their sexual health in the face of breast cancer.

It may also be useful to examine the impact on breast cancer and sexuality using different qualitative methods. In a recent phenomenological analysis on the meaning and experience of female sexuality, Daniluk (1993) chose a group format in which 10 women met once a week for 11 weeks. It was believed that a group format was compatible with the ways "women have been socialized to understand,

communicate, and construct meaning" (Daniluk, 1993, p.55; Gilligan, 1982; Miller, 1986). It may be interesting to explore women's experiences with breast cancer and sexuality in a group format or in a single session focus group in which women can meet together, discuss, and share their experiences with other breast cancer survivors.

This current research may also have implications for those who also research the area of breast cancer and sexuality. Most of the research performed up until this point has focused on such areas as the sexual response cycle, intercourse, and orgasm. In this current research, when the women with breast cancer discussed sexuality, they rarely spoke about areas such as intercourse and orgasms. This may be an important finding for those interested in studying women's sexuality to ensure that what is being studied compliments and corresponds to what is important in women's own sense of sexuality.

Finally, as the participants in this research spoke about their personal constructions of sexuality before breast cancer and how these constructions may have influenced their experiences with breast cancer, it may be important to examine this further when conducting research in the area of breast cancer and sexuality. For example, before researchers conclude that a mastectomy has made a woman uncomfortable with her body and conscious of how she presents herself to the public, it would be important to examine her body image before she was diagnosed with cancer. As a result, concluding that body image suffers as a result of breast cancer could only be addressed after a woman's body image was examined before she was diagnosed with the disease.

Implications for Practice

Some researchers have reported that sexuality for women with breast cancer is often overlooked by physicians and other health care professionals. Women often receive the message that they should be content with being alive and should not worry

about frivolous ideas such as sexuality (Bernhard & Dan, 1986, Burbie & Polinsky, 1992; Ganz et al.,1998). As a result, some women feel that there are no opportunities to discuss sexuality issues with health care professionals. Perhaps part of the difficulty on the part of health care professionals is the lack of comfort in discussing sexuality and the lack of a suitable language when discussing difficulties that women may be experiencing. The themes identified in this research may serve as a starting point for those involved in the breast cancer patient's care when attempting to address sexuality concerns. Perhaps the findings of this current research may aid physicians, nurses, psychologists, social workers and other health care professionals to find the words and language by which to discuss the issues of sexuality for women with breast cancer.

Psychologists and counsellors who work with women who have been diagnosed with breast cancer may find themselves dealing with issues such as sexuality and body image. If women are struggling with sexuality concerns, then it may be helpful to explore their previous understandings and constructions about sexuality. The ways in which women make sense of their sexuality and integrate messages and learnings about sexuality may have a great impact on their sexual self-image after they have been diagnosed with breast cancer. For example, women who have been given messages about the importance of breasts to a woman's personhood and attractiveness may have a more difficult time adjusting to the effects of a mastectomy or lumpectomy. Exploring women's backgrounds and their sexual self-images before cancer may enable psychologists to understand more deeply and to work more effectively with such concerns.

In addition to exploring the pre-cancer sexual self-images of women, it may be helpful for psychologists working with issues of sexuality to examine different challenges that the women may have had to their sense of sexuality since their diagnosis. For example, as witnessed in the literature and in the accounts of the eight

participants in this research, the direct effects and side-effects of chemotherapy can impact different aspects of a woman's sexuality. By educating women, thereby normalizing this experience, about the possibility of side-effects and possible remedies, women may be better equipped to manage these side-effects.

Many women find it a difficult challenge to show their changed physical appearance to their partners. Interestingly, in this research, the participants discussed how sharing their scars with their partners was an integral piece in restoring or recreating their sexual self-images. The responses their partners offered when they initially saw the changes to their bodies was significant to the women's body images. This is a very important clinical implication for health care professionals, particularly psychologists and counsellors. It may be necessary to speak to the couple or the woman's partner to aid in sensitizing the partner to body image issues and the importance of accepting these body changes and supporting their partner in their recovery.

Breast cancer support groups are forums for women who are experiencing similar struggles to meet, share, and ease the labor of cancer and its effects. Oftentimes, issues of sexuality and body image emerge and the women attempt to make sense out of the changes that they have experienced. Perhaps introducing these research results into their support groups might enable them to identify and discuss possible areas of concern and challenge. Likewise, providing a summary of these results to psychologists, physicians, and other health care professionals who work with cancer patients may show that they are actual, tangible concerns that are currently challenging their quality of life.

Conclusion

The focus of this research was on describing the experience and meaning of sexuality to breast cancer survivors. This research allowed women to describe and

share their experiences in their own way, and each woman provided a distinct and unique voice that greatly benefited this research. Although these women came from varying backgrounds, they shared common ground in their fight against breast cancer and their willingness to discuss their personal sense of sexuality. Not only did these women discuss how their sexual self-image and body image were challenged because of breast cancer and its treatment, they also shared how the diagnosis of breast cancer benefited their most intimate of relationships. These eight women have come through a breast cancer experience with a deeper appreciation for their lives, including a fuller appreciation for their sense of selves as women and their sexuality. This is an important message not only for the health care professional that are involved in their care, but also for other women who have faced and are currently facing breast cancer. Certainly, these eight women and their stories can assist those women as they struggle with their own issues of sexuality and survivorship.

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APPENDIX A

GENERAL INTERVIEW GUIDE

General Interview Guide

1. If you could tell a story about your sexuality, or explain what sexuality means to you, what would that be?

2. What kinds of messages did you receive as a child (i.e., from parents, siblings, peers, media) that may have shaped your sexuality?

3. How, if at all, has breast cancer changed your views of who you are as a woman?

4. Has the importance/significance of sexuality changed since diagnosis? If so, how has the importance/significance changed? If not, to what do you attribute the change, or lack of a change?

5. If there was a change in the importance of sexuality, how did they adjust to the change? If there was not a change, would they have liked there to be a change?

6. What role, if any, did your partner play in your recovery?

7. How, if at all, did the way you think about your body change?

8. How, if at all, did the treatment you received for the breast cancer impact your sexuality?

9. Was it significant to you in any way that the cancer occurred in your breast?

10. Can you discuss the role of your breasts in your sexuality?

11. Is there anything you would like to add?

These questions were intended to be used as a guide, and as a result, not all of the questions were included in each interview.

APPENDIX B

STUDY DESCRIPTION

Study Description

This research is being done for a Doctoral dissertation in the Educational Psychology department at the University of Alberta. This particular project is a descriptive study which I hope will provide a better understanding of the meaning of sexuality to breast cancer survivors. By meeting with women, I hope to increase my understanding of their experiences of surviving breast cancer and their subsequent views of sexuality.

Much of the research in the area of breast cancer and sexuality focuses on decreased frequency of intercourse and changes is women's excitement and orgasm in response to breast cancer treatment. Although researchers have broadened our knowledge as to how breast cancer treatment can impact aspects of a woman's sexuality, namely intercourse, the literature on breast cancer and sexuality offers a narrow view of women's sexuality. Intercourse between men and women, the frequency of intercourse and orgasm are mere aspects of sexuality. This interpretation of sexuality neglects additional significant aspects that women may find important. The purpose of this research is to expand and open up the meaning of sexuality for women with breast cancer by interviewing breast cancer survivors about their views and experiences of being a woman with breast cancer. In this way, the possible impact breast cancer may have on women's sexuality can be explored through the women's own perspectives and personal contexts. There is an essential understanding in this research that women's sexuality is personal, unique, and individual.

If this is research that is of interest to you, participation will involve two meetings. The first meeting will allow us to get to know one another. I can share my background with you and you can share your background with me. In this meeting, I will also conduct the interview in which I will ask you to describe your experiences in as much detail as possible. There is no right or wrong answers or right or wrong ways to tell your story. This interview will be tape recorded and later transcribed using pseudonyms for your name and any names that you mention. Only myself and my supervisor will have access to the original tape and this tape will be destroyed once the research is completed. I will analyze the transcribed interview and identify themes which seem to represent your experiences.

The second meeting will involve sharing my understanding of your experiences with you. This time will allow you to provide feedback that supports or contradicts my analysis. My data will be altered as a result of your feedback. Participation is voluntary and you are free to discontinue at any time. If you decide to discontinue, all information about you will be destroyed. The questions I will ask are of a personal nature. Some participants may find the interviews brings up difficult, maybe painful, experiences and reminders. If you find it difficult, I will be happy to provide you with appropriate professional resources. It is hoped that the project will be a positive experience for both you and me.

APPENDIX C

INFORMED CONSENT

INFORMED CONSENT

I, _____, give my consent to participate in Jill Turner's study. I am aware that the nature of this study is to explore the meaning of sexuality to breast cancer survivors, and I will be asked to describe my experiences in as much detail as possible. I understand that the results of this interview will be published as Jill's dissertation for her Doctoral degree, under the supervision of Dr. Barbara Paulson, in the department of Educational Psychology at the University of Alberta.

I understand that my participation will involve two meeting which will last approximately 60 to 90 minutes in length. I understand that some of the questions are of a personal nature and I do not have to answer if I am uncomfortable. I know that there are no right or wrong answers to Jill's questions. I am also aware that this interview is being tape recorded and that my identity, and that of any people that I may mention, will be kept confidential and that Jill will be the only person who will know my real name. Also, I and any others that I may mention will be given pseudonyms to protect my identity and the identity of others.

I understand that the tape recordings will be erased when the study has been completed. I am aware that the interview transcript may be included in the appendices of the dissertation, but I will not be identified. Also, I understand that if my participation in this study raises any concerns for me, Jill will suggest individuals that I might contact for support and counselling.

I am signing this form to show that I have read the consent form and I agree to take part in the study as a participant. I am aware that my consent is voluntary and I can choose to opt out of this study at any time without penalty. I am free to request more information and ask for further explanations if I find necessary. If at any time I have any questions, I can contact Jill at 433-8795.

Signature:_____

Date:_____

APPENDIX D

DEMOGRAPHIC DATA

DEMOGRAPHIC DATA

PERSONAL INFORMATION

The following section asks you to describe yourself so that we know what the overall group of women are like who participate in this research. The confidentiality of responses is guaranteed.

What is today's date? _____

1) What is your date of birth? _____

2) What is your current marital status (check one)?

_____ Single (never married)
_____ Married
_____ Living with partner
_____ Separated
_____ Divorced
_____ Widowed

3) What is the highest grade or level of education you have ever completed (check one)?

_____ No schooling
_____ Finished grade 6
_____ Finished grade 9
_____ Some high school (grade 10 to 13)
_____ Completed high school diploma
_____ Some trade/vocational training
_____ Completed trade/vocational training program
_____ Some college (community college, technical college)
_____ Completed a college program
_____ Some university
_____ Completed an undergraduate degree
_____ Completed a Masters level degree
_____ Completed advanced postgraduate or professional degree (PhD, MD)
_____ Other education or training, please specify

4) Which of the following best describes your situation (check one)?

_____ Working full-time (over 15 hours/week)
_____ Working part-time (up to and including 15 hours/week)
_____ A homemaker
_____ Retired
_____ Unemployed
_____ Not working due to illness
_____ A student

5) If you are not a homemaker, what kind of work did you do, or are you currently doing?

_____

6) Which of the following best describes your partner's situation (check one)?

_____ Working full-time (over 15 hours/week)
_____ Working part-time (up to and including 15 hours/week)
_____ A homemaker
_____ Retired
_____ Unemployed
_____ Not working due to illness
_____ A student

7) If you are living in a relationship, what work does, or did, your partner do?

_____

8) What is your current living situation (check one)?

_____ Live with spouse/partner
_____ Live with immediate family (parents or siblings)
_____ Live with relatives other than parents or siblings
_____ Live with roommate(s) who are not relatives
_____ Live alone
_____ Other, please specify _____

9) Do you have children?

_____ No
_____ Yes. If yes, how many? _____
What are their ages and gender? _____
Are any children living with you? _____

10) In general would you say your overall health is (check one)?

_____ Excellent
_____ Very good
_____ Good
_____ Fair
_____ Poor

11) When were you diagnosed with cancer?

_____
(dd/mm/yr)

12) What type of treatment have you received (check all that apply)?

_____ Surgery
_____ Chemotherapy
_____ Radiation therapy
_____ Surgery, chemotherapy, and radiation therapy
_____ None
_____ Other, please specify _____

13) Is your treatment complete?

Yes _____
No _____

What was the date you completed treatment? _____
(dd/mm/yr)

14) What type of breast surgery did you have (check all that apply)?

_____ Lumpectomy
_____ Mastectomy
_____ Reconstruction
_____ None
_____ Other, please explain _____

15) Were any underarm nodes positive?

_____ No

_____ Yes If Yes, how many nodes _____
_____ Don't Know

16) Before your cancer diagnosis, were you still menstruating?
_____ Yes
_____ No

17) If you were still menstruating at the time of the diagnosis, did the cancer treatment
effect your menstrual cycle in any way?

_____
_____
_____
_____

18) If you were not menstruating at the time of the diagnosis, did the cancer treatment effect your menstrual cycle in any way?

_____
_____
_____
_____